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ABSTRACT

Various quantities and types of services are provided by public and private agencies for older developmentally disabled persons living in the Midwest. Of the 639 questionnaires mailed to public agencies, private agencies, consumer-oriented agencies, nursing homes, and educational institutions, 325 were returned for a response rate of 55%. Overall, 56% of the agencies are providing services for aging and aged developmentally disabled (AADD) persons. AADD clients are "invisible," and few agencies are aware of them, let alone their needs. The existing services are poorly coordinated; adequate records are not being maintained to document services provided. The services most often provided, i.e., information/referral, adult activities, medical treatment, transportation and staff development, are primarily of an indirect nature; most direct services are provided by nursing homes. Major obstacles to service are lack of resources, negative attitudes, and lack of training. Adequate transportation and housing are identified as the greatest unmet needs of the AADD persons. Even if provided adequate funding, most agencies would do nothing new in terms of service delivery. (Author/HLM)

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DOUBLE JEOPARDY

The Plight of Aging and Aged Developmentally Disabled Persons in Mid-America

A Research Monograph

Dwight P. Sweeney and Ted Y. Wilson
Editors

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EDUCATION & WELFARE
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Institute for the Study of Mental Retardation and Related Disabilities

UNIVERSITY OF MICHIGAN
ANN ARBOR

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INTRODUCTION

Ted Y. Wilson

This research monograph fulfills one major objective of a demonstration project sponsored by Grant # 54-P-71134/5 from the Developmental Disabilities Office, Office of Human Development Services, DHEW, to collect, organize, and interpret data on services to aging and aged, developmentally disabled (AADD) persons in the six midwestern states (Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin) which comprise HEW Region V.

Located in Ann Arbor, Michigan, at the University of Michigan's Institute for the Study of Mental Retardation and Related Disabilities (ISMRRD), the demonstration project was funded for three years, from January 1977 until December 1979. Dr. Robert Segal was the original project director, Dr. Julius Cohen was interim project director, and Mrs. Martha Dickerson, M.S.W., was project director for the project's final 15 months.

The editors and authors of this research monograph were staff members at ISMRRD or the Institute of Gerontology or graduate students in educational psychology or educational gerontology at the University of Michigan.

The genesis of this monograph was the hypothesis that persons with two handicaps, being old and being retarded (or otherwise mentally handicapped), needed special attention. Dickerson and her co-authors used their clinical experience in the fields of retardation and gerontology to pursue this hypothesis by visiting selected agencies. They found satisfactory community placements with happy clients, but they also found healthy, ambulatory and comparatively young retarded persons inappropriately placed in nursing homes with older, sicker "normal" persons. Their work, presented at AAMD in 1974 and published for the first time in this volume, strengthened the hypothesis that the aged and developmentally disabled constituted a special population with special needs that were being ignored.

The Developmental Disabilities Office was sufficiently impressed with this hypothesis to fund five projects of national significance to study the AADD population and its needs. Acting as a consortium, the five projects (including the Michigan project) tackled various aspects of the problem. They reported jointly on their findings at AAMD in 1979 in a panel chaired by Mrs. Dickerson.

One of the earliest tasks of the Michigan project was to define the AADD population more carefully. The result was a "Definition Paper" by Nola Thomas and her co-authors. This paper was distributed in May 1978 at the Consultation-Conference on Developmental Disabilities and Gerontology, sponsored by the Michigan project, and is reprinted here in revised and shortened form. The paper argues for clearly defining the AADD populaion in order to organize its members and advocate for them. However, the paper then offers flexible, clinically individualized definitions of both aged and developmentally disabled, blurring the membership of the population and creating a dilemma for advocates and researchers alike.

In order to test the hypothesis that the AADD population has special service needs, Thomas and Sweeney designed a survey questionnaire and tested it locally. A revised questionnaire (see Appendix A) was sent to 639 agencies in Region V (325 questionnaires were returned). Dwight Sweeney reports the aggregate findings of this survey for Region V in his chapter. Only 56% of the agencies responding reported serving AADD persons.

The survey adopted Bureau of Census age brackets (34-54, 55-64, and 65+) in order to be able to compare the AADD population figures from the survey with general population figures. By using the incidence rates for developmental disabilities (either 4.3% or 2.08% depending on severity of disability) Sweeney projected how many handicapped persons one might expect to find in the areas surveyed. He compared these numbers with the number of clients reported by the agencies surveyed. See Appendix B for these calulations which, on the bottom line, show that at best only 12.8% of the projected AADD persons in our country are probably being served. While these calculations must be used with caution, they do suggest that AADD persons in our country are probably underserved and need special help.

The six chapters on Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin provide more specific analyses of the data for each state. Planners, policy makers, and advocates for AADD programs in each state should read these chapters in conjunction with Sweeney's chapter whose larger data set allows more statistically reliable conclusions. In particular comparisons between states, or among kinds of agencies within a state, should be used only as tentative hypotheses for further research.

Although the six chapters on individual states analyze subsets of the same data, each author develops a unique perspective. Salvador Lopez's chapter on Illinois explores the tendency of human service organizations to serve their own needs rather than their clients' needs, especially when the client poulation is ill defined, treatment techniques are not available, and external pressure for service is not being applied--all true of the AADD client population. Jay Levinthal compares the survey data with the Indiana State Plan for Developmental Disabilities and also raises the issue of a third handicap facing AADD people: their poverty. Douglas Ensor's brief essay on the Michigan data makes several striking points, e.g. that AADD clients may get better service from agencies if they remain invisible, i.e. not labeled as DD. Rochelle Flumenbaum looks particularly at the differential treatment of various disabilities by service agencies. She also provides a thorough critique of the methodology of the survey. Jeffrey Ackerman performs an exhaustive analysis of the Ohio data to determine what percentage of clients were being served. Anthony Jackson uses the principle of normalization and its developmental model of programming as a standard by which to judge the types of services (habilitative or maintenance) available to AADD persons in Wisconsin.

Eunice Thurman's chapter on the educational role of UAF's is based on separate survey data collected from UAF's and other selected training units nation wide. The survey questionnaires used appear in Appendix A. Thurman examines the history of legislation affecting the elderly handicapped and in particular the federally supported UAF (university affiliated facility) system. She charges UAF's with failure to provide leadership in training and services to help the AADD population. She acknowledges, however, that such leadership would have required persuading the federal government to change its priorities for UAF funding to include this population.

In practical down-to-earth terms, Judy Cooper's chapter suggests how direct care providers can be trained and supported so they can serve AADD persons more effectively and humanely. This is the mission of a new, three-year grant from DDO to the University of Michigan.

THE AGED MENTALLY RETARDED: THE INVISIBLE CLIENT: A CHALLENGE TO THE COMMUNITY

Martha Dickerson, Jane Hamilton (Cooper), Robert Huber, and Robert Segal

INTRODUCTION

John was going home. At age 55, he had achieved a milestone unattainable for many of us. He was really going home. He was going home after 26 years of alienation from family, from community, from the life stream. At age 29, John had been sent away from his family to live in a huge institution--because his retardation was bothersome and unmanageable to his family, neighbors, and community. He was sent away for "good" and "forever"--or so he and his family believed.

John made a good adjustment in the institution and was happy there. He sharpened his self-care skills, participated in a training program, and developed recreational interests such as fishing, pool, and softball. Twenty-five years passed, reasonably happy years, according to John. He had his friends and an occasional trip to visit family in the city. One day the institutional social worker approached John with the idea of accepting a placement in the community. The whole idea frightened him--to leave his friends of long-standing to return to an unfamiliar city was anxiety-provoking. He resisted the idea, but the social worker persisted, and after months of conversations, John accepted the plan. The convincing argument had been that he would be able to see his family more frequently.

NOTE: This paper was presented at the 98th Annual Meeting of the American Association on Mental Deficiency, on June 7, 1979, in Toronto, Canada.

And so John was placed in a residential setting in the inner city. During the two years he lived there, he worked as a dishwasher, made new friends, learned to enjoy the privileges and responsibilities of privacy that a bedroom all to yourself allows; and began to take independent forays into the near neighborhood. He learned to get to his sister's house by himself--and he enjoyed going there for segments of time--dinner, the evening, or the weekend. Quite without knowing, the idea came into consciousness that to go all the way home would be a good thing for John. With the support of residential workers, and the encouragement of his sister's family, this became a reality and John did go home to live, to find work, to contribute to his community. A success story for John--but not typical of the aged retarded today.

This anecdote suggested to us some of the problems and questions facing the mentally retarded person as he becomes older. Clearly the retarded child image no longer applies.

The Need for Additional Information on the Aged Retarded

The fact that a connection of the Institute of Gerontology and the Institute for the Study of Mental Retardation and Related Disabilities was made for the sake of this paper developed out of an awareness that it was hard for us to find much at all being done in the area of the older retarded person. We have found very little, if any, substantial literature from which to draw. So when we say that the mentally retarded aged are sort of an invisible group, they are invisible in the literature as far as we can see, in both mental retardation and in gerontology. We began our study by trying to figure out just what we should be asking. We asked if there might be any data systems from which we could get information. Could we find out how many elderly mentally retarded people there were in the State of Michigan? We wrote letters to people in gerontology and in mental retardation asking if they knew of any particular programs specifically focused on retarded aged.

A second phase began when we began to ask ourselves questions like: What constitutes a level of retardation that we are talking about? What constitutes a guideline to the definition of aging? We concluded that definitions were not too helpful at this preliminary stage. We concentrated on just who had had experience working with the elderly retarded. With many questions still milling around, we turned to our most available source of experience, the State Department of Mental Health. We asked for the census data about persons in state institutions who might fit the aging category. In the census of the institutions, there were a total of 7,920 persons. From the age of 21 to 44, there were 3,427 people, so a rough fifty percent of the people were within the age bracket of 21 to 44. From 44 to 64 there were 1,111, or twelve percent of the population, and in the age bracket 65, there were 155 persons or one percent of the population.

Some possible conclusions that emerged were: (1) recently, elderly persons have tended to move out of the institutions and into what is, perhaps, euphemistically called a community placement. Therefore, the older populations in these institutions may have been reduced by a current trend toward community placement; (2) the low figures may also indicate that for this particular age cohort there was a lower survival rate. Perhaps, many did not reach age 65; (3) when we looked at some other figures where the census indicated participants in programs such as behavior treatment, rehabilitation, growth development, vocational training, etc. (five categories that the State of Michigan uses to keep a census of what is happening to these people in the institution) we found that the two age groups, one from age 21 to 44, and the older group, had one major activity listed. The category was Adult Activities. Very few, if any, were taking part in education or vocational training. We assume that these adult activities included recreational activities, outings, etc. We assumed that these programs were not particularly designed with any plan of moving the people to any higher level of functioning. It appeared to be a provision for the maintenance of well-being within present settings. We found that in terms of systems wherein one could learn from experience, as long as you stayed within the Department of Mental Health category, we could get at least this kind of census data about institutions. However, once people moved from the institution to a community placement they disappeared. That is, in terms of getting data, they disappeared, because they transferred from the Department of Mental Health to the Department of Social Services. The data channel moves from an institutional population to an individual category: namely, Aid to the Disabled. These persons became part of a system that deals with disability, whether it be from occupational accident, or vocation, etc. Here no records were available, as far as we could find, as to what happened to these people once they were outside the institutions. After several efforts to locate information, we did have some consultations with a number of colleagues.

Finally, we developed some very general premises which we want to explore further. Are there any noticeable trends? Have recent changes in medical practice changed the mortality rate amongst retarded persons? Does this change in medical practice mean that there will suddenly be a larger population of retarded persons who will fall into the aging category in the forseeable future? It does appear that there will be an increase in numbers of persons who will reach this mentally retarded aging category, and that this increase is probably going to come during the 1980's.

The gerontology question (what is old?) is still one we have to define for the retarded person. What appears to be the case now is that for the mentally retarded, the label of old applies at a younger age than for the general population. That is, a mentally retarded person who reaches the age of 45 or 50, we suspect, is regarded as old. (We agreed, by the way, to use 55 as the minumum for aging among the mentally retarded.) We suspect that this early labelling of the retarded as old may be due to the special circumstances of the retarded person as he/she relates to the normal aging or loss continuum.

By middle age (40-55) persons experience loss of parents and some friends, loss of some of his sensory acuteness (bifocals, hearing aids, etc.). We regard this as a normal loss pattern. However, for the retarded this loss pattern becomes a double or triple jeopardy. If he has lived at home with his parents, this loss may result in change of home space. Thus, mentally retarded persons who become older may tend to become part of the life occupant category in long-term care institutions such as nursing homes. There the patients who are mentally retarded tend to be grouped with patients who are senile. (This seems to be another factor in how the mentally retarded elderly person becomes invisible. They get lumped together with these elderly senile persons and their behaviors are not differentiated.)

We note with concern that communities have been slow to develop services for the handicapped elderly. We feel this situation adversely affects the older retarded person. Can the community support handicapped people within the community? We would like to see the development of these community services to maximize the person's functioning within the community as long as it is absolutely feasible. The successes of the movement in locating retarded young adults in community settings demonstrates that the idea is workable. Must age become the consummate insult for the retarded?

SURVEY OF THE SERVICE NEEDS OF THE AGED RETARDED

Two of us operated as a team to explore at first hand a variety of living situations for individuals over the age of 55 who are retarded. The area to which we of necessity limited ourselves encompasses six counties in Michigan with a large metropolitan area as the focal point. We visited six living facilities and a community-based support program, during which time we interviewed 39 residents or participants, the administrators or home operators at each location, and 11 staff people. In every case, the residents interviewed were over 55 years of age. We interviewed no one who was still living at home with no history of institutionalization, and only John, described earlier, who would be returning home.

The range of living environments we experienced varied from the large state institution to a relatively small rural group home. We have tried to achieve anonymity for the sites we visited for they are not atypical, although in each case much of the positive and negative in what we observed was a result of location, financing, staff size, and training, or administrative attitudes. The facilities we visited defined as types are: the state institution, the new privately owned skilled nursing care center, the urban nursing home, the urban board and room house, the urban group home, and the rural group home.

Ten years ago, the largest share of the older retarded people would have been in the large institution, but recent movement toward removal from the institution has shifted the balance to the center. This provides confirmation for the premise stated that "...mentally retarded persons who are older may tend to become part of the lifetime occupant category in long-term care institutions such as nursing homes." We will briefly identify the type of facility, discuss the interviews we held, and draw some conclusions about what we learned from these experiences.

Institutional Care

The place we began in locating the older retarded person was in the large state institution. We interviewed twenty-three people here. Of the sixteen interviewed in the community, eight had lived in this institution, and the other eight in a similar, though slightly smaller, setting.

The institution we visited, like a great many such facilities, was built before 1900 in a rural area . The census is less than half what it was a decade ago with no corresponding decrease in staff. Due to the statewide policy on community placement, those older residents who might have been in the infirmary before, have been placed in nursing homes and the less handicapped have been moved to other kinds of community placement.

Within this institutional setting, we talked with twelve men and eleven women between the ages of 55 and 76. Every resident had lived in the setting for at least 20 years--with an average stay of 38 years. One gentleman had lived in the same building for 60 years. Of the 23 residents interviewed, two would prefer to live in the community, three would consider leaving the institution, and 18 emphatically indicated their wish to stay where they are.

The reasons given by the 18 residents as to why they wished to stay could be summed up in a few phrases. "I'd be afraid to go--there is so much crime." "I'm safe here."

Ray, a former resident of the city, was very explicit. "There are too many murders in the city, too many robberies, too many bad things." He told me that he had been sent to the institution fifty-seven years before so that he would be safe. He experiences his life as reasonably happy. He said that he had needed surgery, which had been provided. He had friends and prior to his surgery had been very active with "his ladies." Down through the years, he had enjoyed working outdoors, mowing lawns, and digging potatoes. Now that he is slightly crippled, he is content to make rugs and indulge in flirtations. "No way are they going to send me away from here."

Ruth was very frightened during her interview. She was fearful that we had come to the institution to force her to live somewhere else. She kept saying, "My sister knows best. She wants me to stay here; besides, I like it here." She said it with such rhythm that we surmised that she had recited it just as vehemently on other occasions. When, with interpretation of the ward worker, she accepted our reasons for being there--she shared with us that some residents referred to Building Two as "Hotel Stay Along", because the men and women had been there for such a long time. Ruth herself had lived there for 33 years. She had been brought there at age 28 when her parents had died.

Sarah would like to try it on the outside. After 52 years in the institution, she recalls that her mother had arranged for her brother to take her to the institution--she never saw either her mother or brother again. Yet, she would like to go back to the city, for that is where she came from.

As stated earlier, she was not typical of the men and women interviewed in the setting for she was the one woman who would like to live outside of the institution.

Skilled Care Center

Next we visited a brand new privately owned skilled care center with all the latest architectural features. All services are provided within the center itself.

We observed and/or interviewed nine aged retarded persons living here. The ages were from 66 to 91. Elizabeth, 70, and Margaret, 82, appeared to be misfits at the Center. They were both ambulatory, verbal, completely able to attend to grooming and eating needs. They had come to this place ten months earlier, after more than 30 years in a state institution. They recall friends and workers from back "there" and appeared to be homesick or lonesome. They have occasional shopping trips in the nearby community. Other than that, their days are spent surrounded by many persons with extreme handicaps. Even their age peers have little in common with them. Ella, called Grandma by the staff, prefers to be alone and spends her days in a wheelchair attempting to sew aprons. Amelia likes to color and play dolls. Mary had no English. Elmer is blind, deaf, and mute, and Ishmen is a toothless mute with cataracts who spends his days holding the hand of a ten year old girl living in a crib.

Attempts are made to involve Elizabeth and Margaret in activities. The day we visited there was a birthday party. However, little interaction appears to occur; rather, many people live their insulated, isolated lives parallel to one another.

It appeared that Ishmen and others were having the skilled nursing attention they needed, but we wondered if Elizabeth and Margaret should or did belong.

Large Skilled Nursing Home

A third kind of facility is the large skilled nursing home located in the inner city. Like many urban locations, this is in a hazardous neighborhood in which staff members leaving after dark are accompanied to their cars by a guard. As there are no supportive services in the surrounding community, the home has been developing its own.

Jim has lived here for three years after 40 years in an institution. He is ambulatory and comparatively independent needing supervision of diet and medication only. He said he was happy for he had friends and responsibility. He is viewed by staff and residents as a competent assistant to the recreation worker. He is solely responsible for the recreational storage room and carries the keys to its door. He expressed no interest in the outside. His world was there.

Hattie had lived in the nursing home for two years after more years in a state institution than she can remember. She recalls coming to Michigan from Tennessee and being placed in the institution when she was 21. She lived there until it became "crowded and full." She said that she is happier now than she has ever been. She goes to the "Read" program and is learning to write her name. She helps the housekeepers around the nursing home by sharing in the dusting and cleaning. She takes care of her room "almost by myself because Alice (the roommate) doesn't like to help." Hattie understands that she must stay in the nursing home because she has diabetes and sometimes seizures. She leaves the nursing home every Sunday to attend church. "A church bus picks us up. I never go out on the streets except Sunday. It isn't safe out there." Hattie enjoys her friends and the parties and Bingo they share within the nursing home. She wishes she had more clothes--and asked us to bring her some--for "I don't have many and I like to be pretty." She had only one regret in her present living situation; "I wish I could see cows. I used to live on a farm a long time ago."

Board and Room Homes

Board and room homes vary greatly in size, and the one we visited was quite large. It, too, is in a low-income, high-crime area of the city. The residents go out in the community to get the services and programs they need. In this community, there has been a program initiated to meet some of the unique needs of the formerly institutionalized adult retarded person.

However, not everyone gets out to programs. Howard has lived there nine years and until last fall, he had never left the home. Last fall a student social worker started to teach him some of the things he needed to know in order to go one block down the street to the activity program. Now he is able to go down there on occasion--but as yet, not alone. Howard is especially attentive to a younger man who is afraid to leave his bedroom and walk around the house--and so his days pass--Tuesday to Tuesday waiting for Miss Rita to come.

Bill has also lived there nine years--after thirty-seven years in an institution. Bill is a friendly, talkative man who enjoys knitting and making rugs. He attends the "Read" group and takes pride in his language workbook. Bill is able to go out of the residence and frequently attends programs at the activity center.

To have a program available close by is not enough if a client needs assistance and support to get himself there. Housekeeping staff do not have the time to provide this service.

The two group homes we visited were very different in both setting and program. One was located in the inner city in a ghetto. The program was designed to be rehabilitative and is staffed by social workers and other professionals. It was from this setting that John went home.

The other group home is located in a rural setting on ten acres of farm and forest land. The staff consists of the woman who operates the home, her two teenagers, and the occasional help of a married daughter.

Albert has lived in this home for ten months after 59 years in an institution. He says, "I'm a happy man." He told of all of his responsibilities and privileges in the home. Daily he is picked up on a bus to go to a nearby activity center. With his friends there, he goes on all kinds of community outings, parties, etc. "They're teaching me how to get along." At home, Albert grooms the two riding horses every day and walks them around the grounds. "I'm never going to get on them. The young ones do that."

He enjoys doing other farm chores--all of which were familiar to him for he had learned them years ago when the institution operated a farm. "I like it here. On Saturdays I earn a couple of dollars working for the neighbors and sometimes I fish in Mum's pond."

Sherman has lived in this home for six months after 54 years in the institution. He and Albert have been friends for years. Sherman is not a very active man. He is recovering from a hernia repair and a heart attack. The bland diet, fresh air, and short walks on the country road are helping him regain his health. "I feel better with warm weather." He enjoys working on rugs--and often sits on the porch watching his friends do the farm chores. "I think I'll stay here, especially if I feel better." When Sherman said that, we wondered what his options were. If he does not stay here, his options probably would be a nursing home or a return to the institution.

CONCLUSIONS OF SURVEY

If much of the focus here seems to be on the state institution, at this point that is because it is the large state institution which had had the most profound effect upon the old, retarded people whom we saw. Wherever they are now, none of them got there without first having been in the institution. All of them had been there at least 25 years. In the past, this was very literally a dumping ground for those who had no place outside. The old institution was the state hospital, the people who lived there were patients, and the focus was on their illness. Lack of knowledge in the field of retardation combined with overcrowding finally removed all vestiges of individuality or self-respect. There are many horror stories about institutions and very few who ever had to live in one and got to leave it would choose to go back. What we have found, however, was that institutions do not have to be like that. They seem to be going through a metamorphosis. Based on what we observed in a facility which may have lived up to all the old stereotypes, the institution can be as human and dignifying an environment as any we have seen.

"Community placement" seems to encompass anything that is not formally a state operated institution. Observing at first hand what happens to people in the name of community placement led us to some indignant philosophizing on definitions of community. Very early in our exploration we found that it was generally true: "...that the patients who are mentally retarded tend to be grouped with patients who are senile." Upon placement from the institution out into community setting the most common designation was "chronic brain syndrome," regardless of what the original diagnosis had been. Additionally, as Mr. Huber has said, in the transfer from the institution to community placement, responsibility transfers from the Department of Mental Health to the Department of Social Services. When the peoople move, their records do not move with them and they drop out statistically because their funds are classified under categorical Aid to the Disabled. It took a lot of back-tracking to determine where people had been prior to placement and whether the original diagnosis had been in fact retardation.

A good nursing home is a good placement for a bedridden patient who needs skilled nursing care. A skilled nursing home in an urban area noted for unsafe streets is not appropriate for someone who spent 40 years living in a country hospital working on the farm if he is ambulatory and needs only supervision of medication. It was with dismay that we realized that 5 of the 16 people we saw in the community were inappropriately placed.

1. Eight years in a board and room home with no access to program is inappropriate.
2. A social, ambulatory person should not have to live in a nursing home

to have his diet and medication supervised. This is especially restrictive if he cannot even safely go out in the street.

3. For two aged, articulate women to live out their days with multiply handicapped, profoundly retarded people of all ages seems to be an inappropriate placement.

It would seem that these people have been inappropriately placed for the second time--the first being 25-40 years ago when they were placed in the institution.

On the other hand, Bill, hooking rugs, learning to read, and going out to programs was obviously happy and he knew it. One of the happiest of retirees is Albert who grooms the horses and loves it. The seven people needing and receiving skilled nursing care were certainly in the right place, and we all rejoice with John who went home. Each of these people represents the work of dedicated and caring staff.

We were pleasantly surprised to see the contentment and dignity felt by the 18 institutionalized clients. We had expected to experience infantilization and patronizing in this traditional setting. We actually experienced these people as being treated with dignity, with respect, and with loving care. For those 18 people we feel a commitment. Their desire to live out the remainder of their lives in the place that has been home should be honored, unless it is possible to find other rural group homes comparable to the one where Howard lives--where small groups of friends can be placed together.

We have trained people who are now 55 and older to accept the security of dormitory living in a rural setting. It is not just frightening, it is terrifying to think of another kind of living. For the most part, they have no kith, no kin, no caring person outside. Inside they have the friendships of 35, 40, even 60 years.

Our experience from this modest sampling leads us to the following recommendations:

1. We have the responsibility to ensure a safe, secure, dignified living for the well aged. This must be provided taking into consideration their long life history. If this happens to be in an institution, we must not feel guilty. We cannot be held accountable for what was done 40 years ago--we must not become guilty by taking them out now if this is the best place just because we remember what the institution used to be.

2. For the aged with health complications, we must find placements in good nursing homes with other aged people.

3. We must move to prepare those who are approaching 55 (maybe even 45) for retirement. Perhaps this means placement out of the institution. We prepare children for school; we prepare people for vocations. Probably this was the biggest lesson we learned. Mr. Huber's figures show a large increase in numbers in this pre-retirement age group. They must not find themselves at 55 and 65 in the same predicament that the present aged are in.

Integrating the Concerns of the Institute for the Study of Mental Retardation and Related Disabilities and the Institute of Gerontology

The Institute for the Study of Mental Retardation and Related Disabilities and the Institute of Gerontology at the University of Michigan became aware that they shared a mutual concern: the elderly mentally retarded. While the Institute of Gerontology has a long history of exploring questions relating to older people, it has placed little, if any, focus on the aged retarded. The Institute of Gerontology has become aware that there is a segment of the elderly populaton which is increasing in numbers, specifically the mentally retarded.

The Institute for the Study of Mental Retardation and Related Disabilities has placed its major focus during the past six years in the area of child development. Its clincial services and training programs have been primarily geared to the needs of infants, children, or adolescents. Little, if any, emphasis has been placed on the needs of the elderly mentally retarded individual. This is understandable since the Institute's primary funding source was the Department of Maternal and Child Health in the Department of Health, Education, and Welfare, Washington, D.C. In addition, during the past few decades the field of mental retardation itself has placed its major focus on the needs of children and the young adult, and has scarcely looked to the older population.

Recognizing this need for a sharing of knowledge and an integration of its resources, the Intitute for the Study of Mental Retardation and Related Disabilities (ISMRRD) and the Institute of Gerontology (IOG) began mutually to explore their overlapping interests so as to determine how best they might develop a joint attack on the problems of the aged retarded person. A task force of representatives from each Institute was organized to explore their mutual concerns. The Task Force consisted of Dr. Robert Segal and Mrs. Martha Dickerson, representing ISMRRD, and Mr. Robert Huber and Mrs. Jane Hamilton, representing the IOG. The Task Force saw as its charge the integration of its mutual interests and the development of joint enterprises that would positively affect services and training programs in the fields of aging and mental retardation.

It became apparent that there has been a tendency for minorities to become invisible within "post-modern" society. This is glaringly apparent in the case of the mentally retarded persons who are now becoming old. The invisiblity of these persons is further highlighted by the general lack of information regarding the presence of these individuals within our communities. There is little data about their needs and even less as to where they may be found in the community. The paucity of such data indicated that both Institutes were almost at a starting point in their search for information.

In order to expand its understanding of the scope of the problem relative to the service needs of the aged retarded, the Task Force of both Institutes called a meeting of professionals working with the aged within the Medtropolitan area of Detroit on March 9, 1974. About 15 professionals participated in the all day meeting. Small discussion groups permitted the conference participants to deal with their concerns in some depth. The concerns raised by these groups indicated the need for continued exploration and the need to obtain additional data about the problem. Some of the concerns the groups raised were as follows:

1. The need to identify the population regarding:
    a. age,
    b. health,
    c. degree of mental retardation, and
    d. present living arrangements (i.e., state institution, nursing home, small group home, etc.).
2. The need to identify the present existing service delivery system and the gaps in needed services.
3. Recognition of the need for better trained staff in nursing homes and other community residential facilities.
4. The need for development of appropriate legislaton to safeguard the legal and human rights of the elderly retarded.
5. The need for research to ascertain the scope of the problem and to examine and evaluate current programs serving this population. Also research studies might be undertaken to learn more about the specific

differences and similarities between the needs and problems of the aged "normal" person and the aged mentally retarded.

It was recognized that there was a need for an expanded conference that could enable other professionals working with the aged retarded to meet and to share their ideas and experiences.

Because the team had numerous questions and concerns regarding the aged mentally retarded, it decided to explore this matter in the following ways: 1) search the literature about this subject; 2) contact agencies throughout the country serving the aged and the mentally retarded to determine what currently is being done to meet the needs of the aged retarded; 3) interview the aged retarded in various types of residential facilities (i.e., state institutions, nursing homes, small group homes, etc.) to determine the resident's adjustment to the residential setting and to learn whether his needs were being met; 4) interview personnel and home operators in community residential facilities to learn more about the facilities and programs and to assess the personnel's attitudes regarding the clients and the program; 5) obtain data from the Michigan Department of Mental Health so as to attempt to identify the number of aged mentally retarded in state institutions and in the community and to learn where they are living; and 6) make inquiries about current research regarding programs or needs of the aged retarded.

Current Trends in Programming for the Aged Retarded

More than 150 letters were sent to various agencies throughout the country involved with clinical, educational, or institutional programs for the mentally retarded to inquire about current trends in programming for the aged retarded. Letters were sent to State Departments of Mental Health, State Associations for Retarded Children, and University Affiliated Training Centers. Follow-up letters were also sent to persons that were suggested by these agencies as possibly being involved in such programs.

About 45 agencies responded. Almost all of them stated that their agency or program was not involved in specifically serving the aged retarded or developing programs to meet the specific needs of the aged. Most were serving children. Many said that their program was geared to meeting the needs of "all the retarded" and did not break down the service in age categories.

The survey indicated that by and large the service delivery designed to meet the needs of the mentally retarded, in general, was not geared to meeting the specific needs of the elderly mentally retarded.

Almost all of the respondants indicated a real interest in the area of the geriatric mentally retarded person and recognized that much more needs to be done in this area. They thought that a conference on a state or national level focusing on this concern would be meaningful and pertinent.

While much still needs to be done throughout our country, some programs for the mentally retarded are being undertaken in various states. Some examples are:

1. Wisconsin:

   The Bureau of Mental Retardation reports that "a few mentally retarded aged do take part in a nutrition program administered by the State Division of Aging. These persons are generally accompanied by an elderly relative, which underscores the transportaton needs of the elderly in general."

2. Louisiana:

   The Division of Mental Retardation reports that some Work Activity Shops include the older mentally retarded person in their programs.

3. Missouri:

The Section of Mental Retardation-Developmental Disabilities of the Division of Mental Health reports "We have just begun a special program at Nevada State School with the intent of analyzing what can be done both with the institutionalized elderly population as well as with many who have often been inappropriately placed in community programs. To date, one of the most encouraging aspects has been the utilization of the Pathways Music Program. Although we have just begun to implement this aspect of treatment services, we are, nonetheless, optimistic."

4. Delaware, Georgia, and Oregon:

The Departments of Mental health in these states report that the elderly retarded have been involved in group homes and foster care programs.

5. Michigan:

Department of Public Health reports that some elderly retarded are served in adult activity centers which provide work activities and workshops. There are also a few recreational services and life consultation services being provided to some elderly retarded.

6. Ohio:

The Board of Mental Retardation reports that "there are a number of aging retarded persons in four or five nursing homes. Many of these persons have been liberated recently from state institutions. They are picked up by bus every day and are taken to their adult activities center where they are involved in a variety of activities including gymnasium. Some of these folks have been moved into the sheltered workshop program. So far they are serving 26 men and women ranging in age up to 75. The County Board provides $450 per person for this activity program. The agency is working very closely with the Welfare Department which is maintaining these persons under Aid for the Disabled. Protective Services are part of the package.

In Cincinnati, the Senior Services Program have a number of retarded senior citizens who are part of their regular program. The staff recognize they must have special awareness of the mental retarded aged and that they may need special attention.

7. Wyoming State School serves aproximately 125 elderly retarded. Its program effort consists of keeping the elderly healthy, active, and involved to their maximum potential. Its primary problem is that of locating facilities at the community level.

8. Travis State School in Texas utilizes the Austin Public Library as sponsors for a new library program for the elderly retarded. The program has proven popular and successful.

Some of the reasons that have been given for lack of programming to meet the specific needs of the elderly retarded are: 1) the present agency objectives are geared to meet the needs of the mentally retarded child or adult; 2) programs for the mentally retarded are provided on a general basis and programs are not set up to meet a specific age group; 3) the agencies are so commited to present services that they do not have staff or funds to develop new programs.

Additional reasons cited are as follows:

a. State of North Carolina reports "I am sorry to say that very little has been done in this state to specifically focus on the elderly person with mental retardaton. Part of this lack of specific program is related to our feeling that in most cases when mentally retarded persons become elderly their programs should be tailored to meet the needs of their problems related to age rather than to mental retardation."

b. The Department of Mental Helth of Tennessee reports that "there are so few geriatric retarded persons in the psychiatric hospitals that there are currently no specialized programs for them that are different from those offered other geriatric patients. Further, the tendency is not to accept mentally retarded patients in the psychiatric hospitals because of the excellent development of mental retardation services to all ages across the state."

While the above reasons for the failure of agencies to initiate or implement needed programs specifically for the mentally retarded aged may have some validity, it is distressing to learn that many are not even contemplating developing such services. Perhaps this may relate to the whole question of priorities and the value society places on the aged and the retarded person, both of whom are generally held in low esteem. Combine these qualities, and the aged mentally retarded is placed in double jeopardy.

Advocacy Programs

Since the elderly mentally retarded are often placed in nursing homes or small group homes with little follow-up, there is a very real possibility that their legal rights may be violated. In order to assure that the elderly retarded are not exploited or mistreated it is important that residential programs are monitored. The elderly retarded may need advocates. While some concerned professionals may play this role along with their other responsibilities, generally the advocate role is not one taken by professionals employed by social agencies.

A recent development emerging is the ombudsman program within some state agencies or community agencies organized for just that purpose.

An example of this is Citizens for Better Care, a grassroots consumer advocacy organization working in the Detroit metropolitan area to improve conditions in nursing homes, homes for the aged, and facilities which house released mental patients.

Citizens for Better Care serves as an advocate for the elderly mentally retarded. Through the Nursing Home Ombudsman Program, a federally-funded demonstration program, people are trained to serve as advocates for patients in particular nursing homes and homes for the aged. In their capacity as patient advocates the ombudsmen assist all patients, including the mentally retarded, by getting answers to their questions, resolving complaints and seeing that individual needs are met. C.B.C. also visits community residential facilities designed to care for former mental patients. Certain facilities house only the mentally retarded, some of whom are aged. C.B.C. handles individual problems of residents in these homes, on an advocate basis, and strives for better conditions in the homes as well as increased community programs and services.

More and more nursing homes are being built exclusively for the retarded, but there is no guarantee that these facilities will meet proper standards, or have enough adequately trained staff to provide high quality patient care. Citizens for Better Care, by directing the attention of governmental agencies and the public toward the geriatric retarded, will be working to make sure that these people are not forgotten.

Survey of Literature

A concerted review of the literature regarding the geriatric aspects of mental retardation was undertaken by research assistants at the Institute for the Study of Mental Retardation and Related Disabilities, and it appeared that little has been written regarding the aged mentally retarded. A search was undertaken by the Institute's librarian utilizing the MEDLARS System (Medical Literature Analysis and Retrieval System)--a computerized bibliographic search of the biomedical literature dealing with geriatric aspects of mental retardation. Only one pertinent article was reported out in that specific search. Most of the general literature in the field of aging and mental health related to the mentaly ill aged person.

In 1968, the Pennsylvania Association for Retarded Children held a Statewide Institute on the Aging Retardate and published the Proceedings of that conference titled: The Aging Retarded. Elwyn, Pennsylvania: Elwyn Institute, 1968.

The format of that conference included a morning session during which three speakers related very generally to the problems of the mentally retarded with a focus on the institutionalized resident. The afternoon was devoted to four workshop discussion groups which discussed a specific case in each workshop. Significantly enough, the ages of the clients discussed were 35, 35, 40, and 30. While the focus of the conferences was to be on the aged retarded, review of the Proceedings indicates that the presentations and workshops seemed to highlight the general problems of the mentally retarded with very little focus on the subject of the geriatric aspects of mental retardation. This may be indicative of where the field of mental retardation was at that time in terms of its understanding or recognition of the problem.

Current Research

Survey of research undertaken in the area of the gerontological aspects of mental retardation indicates that little has been done until quite recently. Some research studies in this area are summarized below:

a. Researchers at the University Affiliated Center in Birmingham, Alabama, have undertaken studies on the survival rate of persons in institutions as compared with the general population. Attention was also paid to the differential survival rate between white and black individuals in that population.

b. Dr. Peter Ulintz at Wayne State University in Detroit, Michigan, is currently conducting a study to compare the behavioral manifestations of the aging process between the aged mentally retarded and the aged mentally ill.

c. Dr. Sara Kriger, of the Department of Mental Health and Mental Retardation of Ohio, has undertaken a needs assessment study titled "The life Style of the Aged Mentally Retarded in the Community," which she began in September, 1973. Her objective is to assess and project the needs of a population consisting of adult (age 40 and over) mentally retarded men and women in Ohio who are currently living in the community, or currently in institutions, but are to be placed shortly in the community. She has interviewed more than 170 persons including the retarded aged, parents, and professionals. Some of the findings are:

1. Agencies serving the mentally retarded generally have little to say about the aged person. They have little knowledge about the needs of the elderly.

2. There is a wide gap in needed services for the elderly retarded with most programs being geared toward the younger group.

3. Those aged retarded who live in the community are not easily identified. No one knew about them and no programs were available, yet they somehow managed to survive. No effort was being made to

identify them.

4. When identified, it was found that the most important central figure in their lives is the home operator. They become extremely dependent upon this person for survival. Despite the important role the home operators play, little training is provided to them.

5. The health and medical needs of the aged retarded were not being met.

6. The elderly retarded are generally satisfied with their living conditions in the community and 90% said they never wanted to return to the Institution.

SUMMARY

Our task force, in its efforts to learn more about the service needs of the mentally retarded aged, undertook the following activities: 1) surveyed the literature; 2) reviewed current research efforts; 3) surveyed current trends in services for the retarded on a national level; 4) interviewed aged retarded persons in residential facilities; 5) interviewed personnel and staff of community residential facilities; and 6) obtained data regarding the aged retarded in Michigan.

These explorations clearly indicated that a great deal more information needs to be gathered about the aged retarded and their needs and that more programs for this group need to be developed. As an outcome of our Task Force inquiries, the following issues and questions were raised that warrant further exploration and study:

1. Do the mentally retarded tend to age more quickly than the normal population? It was noted that many mentally retarded individuals tend to become prematurely old. There seems to be a noticeable physical deterioration in their health condition (i.e., loss of teeth, etc.). Is this premature aging process

directly related to the factors of mental retardation (i.e. chromosomal disorders, etc.) or is it due to poor medical and health care?

2. Are there similarities between the aging process of the mentally retarded and the mentally ill? There seems to be a similarity in their responses and behavior patterns. This might suggest the possibility of combining them in the same programs and facilities.

3. To what degree is the aging process of the mentally retarded more pronounced because, historically, they have not learned self-care skills or have severe limits placed on their educational opportunities?

4. Do the aged mentally retarded residing in state institutions tend to live longer than the aged mentally retarded residing in the community?

5. It was noted that house parents in group homes and paraprofessionals responsible for the care of the retarded aged in nursing homes tend to infantalize the aged retarded. What is the basis for this behavior and what are the best methods to alter it?

6. At times, it is difficult to find the mentally retarded aged once they have been discharged from state institutions. For example, when they are placed in a nursing home their records often do not follow them and the staff often are unaware of their background or specific needs. What kinds of organizational procedures need to be devised to help the community resources be more aware of the special needs and background of this population? Sometimes an aged retarded person might be placed in a small group home and subsequently forgotten since little, if any, follow-up is ever undertaken.

7. Why have so few surveys been undertaken to carry out case findings regarding the identification of the aged retarded in the community? Agencies serving the mentally retarded seem interested in identifying children or adults so as to develop programs for them, but they do not seem as interested in the

aged retarded. Is such small value given to this older population?

8. It appears that while much concern has been expressed about preparing the normal person for the aging process, little thought has been given to preparing the adult retarded for old age. There may be a need to develop programs in state institutions and in community group homes that prepare the adult retarded person to handle the problems that may arise during the aging process.

9. It appeared that many of the mentally retarded aged seemed to have bypassed the "middle age" phase. Many moved from childhood to a prolonged adolescence into the phase of being "old". To what degree is this related to the factor of mental retardation or to the way they were handled or programmed by society or the environment in which they lived?

10. To what degree is the fact that many of the mentally retarded aged seem fairly satisfied living in the community outside of the state institution due to their lifelong pattern of dependency or because the placement is a meaningful and satisfactory one for them? Would the mentally retarded aged be happy "anywhere" as long as their basic needs for food, shelter, and clothing were adequately met?

11. To what degree are the mentally retarded aged different from the more normal and aged person? Some professionals and agency personnel contend the problems of the aged retarded are similar to the problems of the normal aged and therefore, no special concern or attention is required relative to the needs of the mentally retarded aged. This view has serious implications for the development of specialized programs for the aged retarded.

AGING AND AGED DEVELOPMENTALLY DISABLED PEOPLE:
DEFINING A SERVICE POPULATION

Nola Thomas, Peggy Acker, Linda Choksey, and Julius Cohen

INTRODUCTION

As a segment of the adult population, developmentally disabled persons are entitled to the same rights, privileges, and treatment which accrue to any citizen, regardless of special needs. However, they are prevented from fully participating in the culture, and reaping its benefits, because they are not identified as a powerful group at this time; they do not advocate for themselves. They are not seen as part of the increasingly vocal non-disabled elderly population, and they do not have an absolute place in the planning for developmentally disabled persons. Their lack of visibility causes them to be excluded from services within both the aging and developmental disabilities arenas. These political realities, which involve the allocation of public resources, are compelling reasons for defining the aging and aged developmentally disabled population. A common terminology and accurate descriptive information are requirements for creating a viable constituency and empowering representatives to act on behalf of this relatively ignored group--a prerequisite for obtaining equal treatment.

By developing a comprehensive definition, the authors hope to establish a meaningful vocabulary and conceptual framework which will act as a foundation for expanding knowledge and providing a unified approach toward studying, and providing services to, this population.

DEFINITIONS OF AGING

"Aging," as an index for change, is based on our notions of time. It consists of those biological, sociological, and psychological processes usually associated with steadily progressive change that individuals characteristically undergo as they move from a state of full physical maturity through the adult phases of the life cycle toward old age and death. A person's chronological age is the sum total of the number of years that have occurred during his/her lifetime. Accordingly, we might say that aging begins at conception, or at least at birth, when the organism is first exposed to the forces of change. The terms "aging" and "development" have been used interchangeably to represent the sequential phases of the human life cycle consisting of four major stages: growth, maturation, plateau, and senescence. The term "development" encompasses all four stages; the term "aging," however, is more commonly used to refer to those changes that are characteristic of the last two stages of the life cycle: plateau and senescence.

Some theorists have drawn an analogy between the stages of life and the seasons of the year, describing the early years as "characterized almost entirely by growth of the organism and by enlargement, differentiation, and refinement of capacities . . .," and the middle and later years "by decline, decrement, and loss of function" (Tibbits, 1960). This growth-decline life cycle paradigm is predominantly based on the biological model of development. Other theorists stress that psychological, social, and behavioral facets of aging interact to determine the nature, extent, and rate of aging. As we move away from the traditional, biologically-oriented model, it becomes clear that there is continued potential for growth and development during middle and late adulthood if we recognize the many facets of life-long human development.

Biologists, as yet, have been unable to isolate the agent that triggers the aging process. Unless they are able to uncover the mystery of aging, definitions of aging and old age will necessarily be formulated from observations of stages that organisms undergo as a result of the aging process. Most of the suggested causes of aging have proven to be manifestations of, rather than mechanisms for, aging. Because the cause of aging is still unknown, each profession concerned in some way with the phenomena of aging has been left to offer an interpretation of the aging process from its own perspective.

There are three basic perspectives on aging--biological, social, and psychological--from which a variety of disciplines derive their interpretations. These models or perspectives on aging are briefly defined and described below. Because human beings change not in parts but as whole persons, the biological, social, and psychological factors in aging are best understood as interacting forces with a resultant overall direction and rate. Analyzing the different perspectives on aging should contribute to, rather than supplant, a holistic understanding of the aging process in human development.

Biological Aging

As a system ages, it undergoes pronounced changes in its properties and characteristics. From a medical point of view, these changes accumulate and impinge upon the organism's ability to cope with stress. The changes that specifically occur as a result of the process of aging are generally seen as functions of primary aging. These changes have been contrasted to secondary aging, or alterations in organic funtioning attributable to disease and/or environmental factors.

Human longevity is probably determined by biological factors, with an upper limit beyond which human life cannot exist. However, environmental conditions such as diet are known to affect average life-expectancy.

Biological aging occurs in cells, tissues, organs and systems. Changes in cells and tissues account for alterations in physical appearance, such as wrinkling of the skin or fading of hair pigment. Some of the more common systemic changes occur in the cardiovascular, renal, respiratory, and immune systems. Changes in body composition, loss of stature, lowering of basal metabolic rate, and the loss of sensory acuity also occur as aspects of primary aging.

The altered physiologic characteristics of aged persons reduce their ability to maintain homeostatic balance under stressful conditions. Aged persons, due to overall changes in their physical health, are particularly susceptible to certain acute and chronic ailments.

It has already been noted that little is known about the onset of primary aging processes. Kimmel (1974) believes, moreover, that "it is difficult to isolate normal effects of aging from pathogenic changes," and that what now seem to be "normal age-changes" may eventually be found to be "disease processes" (p. 357). If this were the case, then biological aging could be defined in terms of disease. However, most definitions of biological aging assume that those changes occur in the absence of disease in the entire aging population.

Biological aging, then, can be defined as a set of time-related processes that account for the deterioration of the mature organism's susceptibility to external stress with advancing age and thereby increase the probability of death as a function of age.

Social Aging

Society decrees certain conditions and states that qualify individuals as having an aged status. Several social theories have been proposed to explain the "coming of age" and reasons for the transition to the oldest social age grouping. The most popular of these theories are the disengagment theory proposed by Cumming and Henry (1961), the life review (Butler, 1968), and the activity theory (Maddox, 1963).

The disengagement theory is based on the functionalist doctrine that society and the individual mutually disengage in preparation for the ultimate disengagement from life: death.

One of the final stages of disengagement, the life review, is the process of examining one's life in retrospect. In theory, disengagement and the life review are developmental processes. Personal life is given new meaning and significance through the reorganization and reintegration of past experiences.

Unlike the disengagement theory, the activity theory explains behavior in old age from an environmental rather than developmental perspective. Activity is maintained throughout the later years so long as options remain open to the older person. Criticism of the disengagement theory led to a formulation of the activity theory, stating that activity, rather than disengagment, is the normal behavioral pattern throughout the later years.

The disengagement and activity theories of aging generalize the character, motivations and drives of persons in their later years. A broad perspective on the aging experience is recognition of the fact that there are many patterns of reaction to old age. An older person's behavior is determined by past experience, and present functioning and circumstance. As people age, they become more disimilar and individualistic as their life circumstances become highly diversified.

With the coming of age, many older persons discover that society offers little in the way of positive role identification for the elderly. The older person may be forced to identify with a youthful image so as to maintain positive self-esteem. Life satisfaction in the later years can be low because older persons often hold negative views toward aging and old age, yet cannot successfully disassociate themselves from this role.

Social aging is concerned with: 1) the processes of societal age-grading of acceptable behavior; 2) the individual's adoption of habits and roles relative to these expectations; and 3) his/her competence, as a function of age, in carrying out these roles. Status, self-esteem and life satisfaction-psychological components, are directly related to social roles.

Related to the sociological aspects of the aging process, is the establishment of the legal definition for "aged." In our society, age 65 was arbitrarily chosen by the drafters of the Social Security Act of 1935 to design a system which would ensure an income for retired or disabled workers and their families. For a number of social services for aged persons sponsored by the Older Americans Act, the age of eligibility is lowered to age 60. The essential difference between "aging" and being "aged," however, appears to be a question of "age-grading" and the degree to which aging processes are visible. A scientifically accurate point of demarcation generalizable to all persons continues to elude researchers.

Psychological Aging

In general, psychological functioning declines with age. However, many psychologists believe that age-related changes rarely interfere with skills and attitudes required for normal life activities.

An increasing personal resistance to change, decreasing receptivity toward novel ideas and situations, and conservativism and cautiousness are characteristics generally associated with old age (Botwinick, 1973). As people age, their resources or power may be exceeded by demands upon their reserves. This accounts for the tendency among older persons to respond in a rigid and conservative rather than flexible manner.

Alterations in sensory, motor and cognitive functions with age do not necessarily produce handicapping conditions. It has been found that such variables as physical fitness, task rehearsal, and motivation can marginally reduce age differences in reaction time. In addition, compensatory skills may often be developed. These findings have had great implications regarding the retraining of older workers in manual activities and the training of younger developmentally disabled persons in work skills.

One theory that could put an entirely different perspective on intellectual decline in old age is the terminal drop theory: a sharp decline in cognitive abilities in those who are close to death (Kleemeier, 1961). Studies have shown when an elderly person begins to perform poorly on traditional IQ tests he or she may be near death. It has been suggested that the apparent decline in intelligence for aging persons found by some theorists may in fact be caused by the terminal drop phenomenon in some of the subjects tested.

Late life crises and critical developmental tasks can cause profound grief and loneliness in the elderly. The death of a spouse, relative, or friend can reduce social interaction and disrupt the survivor's sense of security. In addition, security is threatened by recurrent changes in living arrangements and possible separation from family. Retirement and/or invalidism of a spouse can strain marital relations and may result in role changes and dependency reversal. Loss of personal dignity and self-esteem can result from a number of variables, including sudden or gradual physical disabilities, retirement, inadequate role identification, and inferior social status.

Psychological aging, then, refers to age-related alterations in the adaptive capabilities of adults, and to changes in personality, psychomotor and cognitive functioning. Psychological problems in later life are generally thought to be the continuation of trends that began at an earlier stage in adulthood. Abrupt declines are not, however, uncommon and drastic changes in personality and cognitive faculties can occur for a number of reasons, ranging from physiological disorders to social maladaptation.

DEFINITIONS OF DEVELOPMENTAL DISABILITY

Like "aging," the term "developmental disability" encompasses biological, social, and psychological variables which are variously emphasized by different professions and social systems. Unlike aging, developmental disability is never a "natural" process.

The word "disability" is most often used to refer to intellectual, emotional, and physical impairments of the human organism. The "age of onset" of a disability is considered an important element in determining the etiology, impact, and progress of the the impairment over the lifetime of an individual. When a disability occurs can influence "how much" and in "what ways" a person is going to be affected. Hence, a disability incurred during the developmental or "growth and maturation" phases of the human life cycle can render a person more vulnerable. A disability may be identified either as synonymous with its etiology or with the effects of its etiology. Such words as quadriplegia, amputee, organic brain syndrome, mental retardation, epilepsy, alcoholism, rubella syndrome, cerebral palsy and Down's syndrome can refer in confusing fashion to either a disability's origin or its symptom manifestation. These terms, however, say nothing about the impact of these disabling conditions on any given individual. Certain social situations in combination with one or more of these conditions may or may not not put an individual at a significant disadvantage in carrying out life's tasks; the person may be disabled but not therefore "handicapped." In other social situations, a less significant impairment may prove a serious handicap.

In response to this lack of clarity, and to the need for exclusive qualities of categorical labels, the Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978 (P.A. 95-602) redefined the term "developmental disability." Whereas, previously, categories such as mental retardation, epilepsy, autism, cerebral palsy, and related neurological disorders were identified as developmental disabilities, these amendments redefined "developmental disability" as a "severe and chronic disability" which meets the following criteria:

A) is attributable to a mental or physical impairment or combination of mental and physical impairments;

B) is manifested before such person attains age twenty-two;

C) is likely to continue indefinitely;

D) results in substantial functional limitations in three or more of the following areas of major life activity:

  (i) self care,
  (ii) receptive and expressive language,
  (iii) learning,
  (iv) mobility,
  (v) self-direction,
  (vi) capacity for independent living, and
  (vii) economic sufficiency; and

E) reflects the person's need for a combination and sequence

> of special, interdisciplinary or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.

In this manner, the law enlarged the concept of developmental disabilities to include persons with diverse impairments but similar functional limitations while holding to an age limitation. Like the legal use of age 65 to determine when a person is aged, chronological age considerations still hold sway in the U.S. schema of human needs. Fortunately, built into the law is the provision that DHEW analyze the impact of the use of this new definition and report back to Congress by 1981. The actual operation of so broadly based a definition needs to be monitored. Among other things, these amendments also change the scope of rehabilitation programs for developmentally disabled adults. If these new amendments are universally and honestly applied, many aging and aged persons who previously did not meet the categorical criteria, may be considered developmentally disabled and hence eligible for the services and rights to which this group is by law entitled.

AGING AND DD

Individuals who sustain severe physical, intellectual, and/or emotional impairments during the developmental phases of their life cycle nevertheless continue to grow, develop, and age within the parameters of their capacities and the restrictions of their environment. As they attain full physical maturity, they progress through the adult phases of the life cycle and experience old age and death. More needs to be understood about the unique biological, psychological, and social characteristics which accompany their aging process so that truly helpful and humane intervention programs may be implemented.

Biological Considerations

Because developmentally disabled people are usually physiologically or neurologically impaired early in their lives, the difficulty in distinguishing between primary and secondary aging is further complicated for this population. As questions about the universal characteristics of aging are still unanswered, it is difficult to know what biological phenomena in DD persons are to be considered symptoms of "aging" rather than environmentally induced disease, insult, or trauma. At the same time, it is vitally important to make such distinctions for all aging persons, particularly the developmentally disabled, for whom misdiagnosis or misunderstanding can have dire results.

Obviously, no intervention can be effective if it does not address itself to the underlying causes of a given condition. For example, an elderly person who is considered "senile" and who therefore is not further examined may never be recognized as undernourished and vitamin deficient. It is not enough for a person to "look old" and to be given a label of "aging or aged." In this day of consciousness-raising on every topic, professionals in both gerontoloty and developmental disabilities need to take a long look at their subjective, often presumptuous, expectations of client behavior. Dr. Sidney Kaplan, Director of Western State School and Hospital (1968), offered these still valid words of warning with regard to treating retarded persons as if they were aged:

> The retardate, whose communicatin skills are severely limited, is apt to be treated like a much older person. He lives apart from the mainstream of even his limited environment.
>
> The point being emphasized is that there are many factors that are influences on the judgment of the person's age. More importantly, how we judge the retardate largely determines how we will relate to him and this in turn can influence the speed at which he ages. We have it within our power to age these retardates at a quicker pace. (p. 2)

Kaplan's comments apply not only to the retarded person but also to the aged person who, having faced a life free of disability, finds himself treated in a stereotypic manner once he demonstrates even the most minor physical characteristics, wrongly or rightly, associated with aging.

Developmentally disabled persons may live shorter lives and age earlier than other persons because of their physical problems even though modern medicine has decreased their mortality rate. These are areas which have received little, if any, systematic research. With the exception of Pregoria, a premature aging syndrome associated with mental retardation, most of the work in this area appears to have been done with persons having Down's syndrome. It is known that pre-senile dementia or Alzheimer's disease is present in middle-aged persons with Down's syndrome (Dalton & Crapper, 1977). Other researchers have demonstrated that retarded persons do deteriorate somewhat in functional abilities such as vision and hearing just as non-retarded aging persons do.

Nevertheless, there remains a great need to examine further the biological aspects of aging for developmentally disabled persons through longitudinal studies and other research techniques.

Psychological Aspects

Much more needs to be known about the psychological functioning of adult and aged developmentally disabled persons. Adaptive and compensatory skills for coping with life tasks may continue to develop in spite of manifest intellectual decline. One study of DD adults (Bell & Zubeck, 1960) showed that IQ did not decrease over time. The same conclusion has been drawn from other studies with DD persons (Jarvick & Faleck, 1963).

Other studies substantiate the idea that intellectual decline does occur in persons close to death (e.g., Lieberman, 1965). This theory may be related to the idea that developmentally disabled persons, particularly the retarded, die earlier than their non-disabled peers. In this regard another author (Eisdorfer, 1969) has pointed out that: "This area of study is in its earliest stages . . . and the relationship between more subtle forms of central nervous system (CNS) functioning and survivorability [sic] needs more investigation" (p. 103).

The need for more longitudinal studies of developmentally disabled persons with similarly diagnosed impairments into their older years is needed. It is expected that such research will demonstrate that developmentally disabled persons behave similarly to their non-disabled peers, for example, that they will be more inflexible and cautious in response to their diminished energies and capacities. As there is disagreement as to whether or not these and other characteristics are universal psychological concommitants of aging, studies with DD persons may help make the necessary distinctions. Increased understanding about effects of aging on brain disease, damage, and related syndromes, would be fruitful.

Most older adults face psychological crisis (e.g., death of a spouse) related to developmental tasks of the adult-phase of the life cycle; they adjust to changes in intrapsychic and interpersonal status in a somewhat predictable way. Eric Erickson, (1959) for example, describes the crisis of adulthood as generativity vs. stagnation; and finally as integrity vs. despair. These crises, he says, have both a psychological and a social component.

For most developmentally disabled adults, the psychological aspects of the crisis of adolescence, identify vs. role diffusion, are never fully resolved because of their roles in this social structure and therefore, interfere with later life satisfaction and adjustment. They have also had to face a longer struggle for self-esteem as they have had to adjust to lowered intellectual and physical capacity at an early age, something which most persons confront as a late life crisis only if they then become socially, physically, or intellectually impaired.

Social Aspects

For developmentally disabled persons, an understanding of the relationship of social environment to psychological and social functioning is one which is particularly urgent. The concepts of "maximizing personal potential," "deinstitutionalization," and "normalization of environment" have been promulgated as preferred treatment.

In this regard, Wolfensberger (1977) states:

> When a person is perceived as deviant, he is cast into a role that carries with it powerful expectancies . . . Unfortunately, role-appropriate behavior will then often be interpreted to be a person's "natural" mode of acting, rather than a relatively plastic mode elicited by environmental events and circumstances. (p. 131)

In the social arena, the adult developmentally disabled population has been treated in the same way as the aged population. Both groups are "cast" into similar social roles, namely, roles which reflect poverty and lack of control.

With the non-disabled elderly, self-help or "consumer" groups are fighting this socially inferior status by demanding role and age appropriate programs controlled by senior citizens. These groups are changing the attitudes of the public. On a very small, but growing scale, developmentally disabled adults have begun a similar movement through the self-help groups called "People First" begun in Oregon by a retarded, married man named Mr. R. Loomis. This group has grown in numbers and has held a conference which the members organized and implemented. "People First" has demonstrated that developmentally disabled adults of all ages can find a meaningful, not artificial, place in society, a place which allows them satisfaction for all their human needs.

It is difficult to say whether or not the sociological theories of "disengagement" and "life review" are applicable to the aged developmentally disabled. Clearly, experience shows that many developmentally disabled persons are not only aware of death and life's problems and joys, but can often express their awareness of these to others, individually or in groups. In their paper "The Invisible Client: The Aged Retardate, A Challenge to the Community," Dickerson, Hamilton, Huber and Segal (1974) note that many aged retarded people living outside state institutions seemed fairly satisfied regardless of the adequacy of their placement. They appeared adjusted to the limitations placed upon them by their impairments and society. This satisfaction was also reported by Kriger (1975).

Although death is the final disengagement from life, the extent to which a person disengages depends upon the individual's personality and the resources available to him in the community. This would seem to confirm the need to intervene with appropriate services in the lives of aging and aged developmentally disabled persons, in order to mitigate their disengagement from the community and from active involvement with life at a much earlier age than would be expected for other aging persons. The aged person normally has a history of active social engagement which the developmentally disabled person usually lacks. Kriger (1975) believes that the lifestyle of an aged, retarded person cannot be compared to that of an aged non-retarded person because the latter has usually had formal education and active participation in the labor force giving that group a social advantage over any developmentally disabled group. Services for developmentally disabled adults have only recently become the focus of programming attention and the potential impact of this on later life adjustment is not yet known. The right kind of programming for developmentally disabled adults may still mitigate the effect of their poor previous training and education and minimize their "disengagement" from life activities at an early age.

For the most part, aged developmentally persons have not been treated as though they need to remain "active" and engaged in social activities. A prevailing attitude has been to focus attention on younger, more "trainable" developmentally disabled people and to let the older group "disengage" or become custodial wards.

CONCLUSION

This paper attempts to define what is meant by "aging and aged developmentally disabled persons."

When developmentally disabled persons reach physical maturity, they begin aging biologically, that is, declining in physical capacity. However, psychological and emotional decline does not necessarily follow; rather, there is continued development in these areas throughout the life cycle, within the parameters laid out by social structure, environment, and the person's innate potential.

The papers which follow discuss the findings of a survey conducted in each of the states of Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin. At the time the survey was carried out, the federal definition of developmental disability was a categorical one. The new "functional" definition of a disability may pave the way for a more accurate system of data collection.

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DENIED, IGNORED, OR FORGOTTEN?: AN ASSESSMENT OF COMMUNITY SERVICES FOR OLDER/AGED DEVELOPMENTALLY DISABLED PERSONS WITHIN HEW REGION V

Dwight P. Sweeney

PROBLEM

Although the special plight of aging and aged developmentally disabled (AADD) persons was first discussed by Dickerson, et al. in 1974, this group is only slightly more visible today. This apparent lack of progress could be attributed to the notion of "double jeopardy" raised by Dickerson and her co-authors, but more skeptical observers might raise the possibility that there is no such population group as AADD persons. Both of these possibilities will be considered in the discussion which follows.

In the fall of 1976, the Institute for the Study of Mental Retardation and Related Disabilities (ISMRRD) of The University of Michigan was awarded a three-year grant to conduct a study of services available to AADD persons. The grant, one of five to University Affiliated Facilities in Georgia, Utah, Michigan, Nebraska, and Oregon, was awarded by the Developmental Disabilities Office, U.S. Department of Health, Education and Welfare, and funded as a Project of National Significance through Public Law 94-103. The Michigan project, entitled "Serving Aging and Aged Developmentally Disabled Persons," made the collection, organization, and dissemination of current data on the client population a major objective. It was hoped that such data would prove useful for planners and decision-makers at all levels who are responsible for program development.

Although community services for older/aged developmentally disabled persons were known to exist (e.g., Social Security, Medicare, etc.), information as to the type, number, and impact of these services was not readily available. The first national conference on aging and developmental disabilities was held in 1975 (Segal & Hamilton, 1975). After that several studies examined various sub-sectors of the population (Gordon, 1977; Hamilton & Betts, 1977; Hanf & Kieter, 1977; etc.). However, as yet there has not been a systematic and comprehensive collection of data addressing the demographic characteristics or special needs of AADD persons. Further, while prevalence rates for mental retardation, epilepsy, cerebral palsy, and autism have been established for the school age population, no similar figures exist for older adults. Hanf and Keiter (1978) even raised questions about the differential longevity of developmentally disabled and normal elderly persons.

To rectify this lack of information, the project staff decided to collect demographic information on AADD persons and attempt an assessment of the community services being provided to this population. The project staff felt there were four central questions:

a. How many AADD persons were receiving services from the agencies surveyed?

b. What kinds of services were being provided to this population?

c. What additional services were needed by AADD persons?

d. What were the obstacles to effective service delivery?

To collect this information, the project conducted a sample survey of community services available to AADD persons throughout HEW Region V.

METHODOLOGY

The Questionnaire

The feasibility of collecting data from service agencies was unknown, so a pilot survey was first undertaken within Michigan. Collecting information from agencies regarding their clients and the services provided to them presented several problems in questionnaire design. Other researchers (Hanf & Kieter, 1978; Hitzing, 1978; Hamilton & Betts, 1977; Gordon, 1977) had reported difficulty in getting either client-specific information or direct access to clients, especially when clients resided in institutions or nursing homes and the researcher asking the questions was associated with an agency or institution with a reputation for client advocacy. Even with access, researchers reported that records were not generally kept by categories specifically pertinent to AADD persons. Thus, the questionnaire needed to be unobtrusive enough not to threaten but definitive enough to be of use--a compromise at best (Webb & Campbell, 1966).

A pilot questionnaire was distributed to 27 agencies in Washtenaw County, Michigan, known or believed to be providing services to AADD persons. Twenty-three (23) agencies responded to the pilot, and a revised questionnaire was constructed.

An addendum questionnaire was also developed to assess services and training provided to AADD persons by University Affiliated Facilities (UAF's). The UAF survey is reported elsewhere in this volume.

Specific information sought by the revised community assessment survey included:

1. number of agencies serving AADD persons;
2. number of clients served and their age;
3. types of disabilities agencies worked with;
4. range of services provided to AADD persons;
5. frequency with which services were actually rendered;
6. identification of unmet needs;

7. identification of unserved clients;
8. sources of program funding; and
9. existing/perceived barriers in provision of services to AADD persons.

A major finding of the pilot survey had been that neither agency employees nor their administrators understood what developmental disabilities were. In spite of the record-keeping requirements of state plans and past requests by state DD Councils for such data, few agencies were able to furnish information about their clients' ages or disabilities. Therefore, to make the questionnaire more comprehensible and informative to the agencies a list of definitions, a brief description of the DD Act, and an overview of the goals and objectives of the project were included with each questionnaire. It was hoped that this information might be helpful in filling out the questionnaire and educational for those agencies which, for one reason or another, elected not to participate in the survey. It was further hoped that the specific questions about age and disability types might prompt some agencies to begin keeping records by those categories if they were not already doing so. A copy of the final questionnaire and cover letter is found in Appendix A.

The Sample Population

The sample population selected for the survey was intended to be representative of HEW Region V. One principal urban area and one university community were chosen in each of the six states in Region V. The urban areas were selected because census information showed large numbers of elderly persons concentrated in metropolitan areas. We also believed that human services are usually concentrated in urban and university communities, and further, that university communities would be more likely than other communities to provide experimental services as part of their training programs. Thus, it was felt that if major gaps in services appeared in these service-rich areas, it might be reasonable to assume that these services were not being provided anywhere else either. The cities selected for the survey included:

STATE	URBAN AREA	UNIVERSITY COMMUNITY
Minnesota	Minneapolis/St. Paul	Duluth
Wisconsin	Milwaukee	Madison
Illinois	Chicago	Champaign/Urbana
Indiana	Indianapolis	Fort Wayne
Ohio	Cincinnati[1]	Columbus
Michigan	Detroit	Marquette
		(Data from Ann Arbor was available from the pilot but not included in this report.)

Once the cities had been selected, a list of public, private, and consumer agencies, as well as nursing homes, public schools, and colleges/universities was compiled from local telephone directories utilizing the list of key words below.

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[1] While the project would like to claim that the reason Cleveland was not included in the sample was that it had already been surveyed (Kriger, 1975), the truth of the matter is that a research assistant sampled the wrong phone directory at the library, resulting in Cincinnati rather than Cleveland being included in the sample.

Survey Key Words

- Nursing Homes
- Retirement
- Goodwill
- Salvation Army
- United Way
- Community Services
- Group Homes
- Half-Way Houses
- Aging
- Senior
- Independent Living
- Vocational Rehabilitation
- Mental Health
- Mental Retardation
- Nutrition
- Recreation
- Homemakers
- Legal Assistance
- Lawyer Referral
- Association for Retarded Citizens
- Planned Parenthood
- Consumer
- Public Schools
- Colleges/Universities
- Social Services
- Social Security
- Welfare
- Education
- Adult
- Special Education
- Developmental Disabilities
- Human Services
- Protection
- Advocacy

All of the public, private, and consumer agencies, as well as the public schools and colleges/universities were recorded. In addition, a systematic sample of one-fifth of the nursing and retirement homes was generated by selecting every fifth home from the telephone directory after a random start. This technique yielded a sample of agencies which was estimated to account for 40.7% of the non-institutionalized population of Region V (See Appendix B, Population of Areas Surveyed).

Surveying agencies rather than individuals offset some of the difficulties of sampling from telephone directories (Warwick & Lininger 1975; Babbie, 1973). However, lack of a definitive epidemiological study or census of AADD persons made computation of a sampling error virtually impossible because there was no standard population to use for comparison. We didn't know how big a pie we were taking a cut of.

Response Rate

The questionnaires, definitions, and cover letters, along with a stamped, self-addressed return envelope were mailed to 639 agencies within the region. After approximately four to six weeks, a follow-up packet was mailed to those agencies which had not responded to the original mailing. In spite of the limitations of sampling from a phone directory (outdated listings, lack of specific office addresses and/or zip codes), only forty-six of the questionnaires were returned with bad addresses. Of the 639 questionnaires mailed, 325 were returned completed by the cut-off date, for an overall response rate of 55%. The response rates by states ranged from a high of 63% from Minnesota to a low of 47% from Illinois and Ohio (See Table I). Table I provides details about responses to the survey. Babbie (1973) has indicated that any response rate to a mailed questionnaire which exceeds 50% is sufficient for analysis and limited inference. Thus the response to the AADD questionnaire is sufficient to draw some general conclusions concerning service to AADD persons within HEW Region V. However, in many cases, what we didn't learn was more significant that what we did.

Table 1

Survey Response Rate

STATE	Number Mailed	Bad Address	Number Delivered	Returned Completed	Response Rate
Michigan	149	4	145	86	59%
Wisconsin	95	6	89	55	62%
Illinois	109	11	98	46	47%
Minnesota	78	7	71	45	63%
Indiana	71	7	64	38	59%
Ohio	137	11	126	55	47%
Region V	639	46	593	325	55%

Data Analysis

The inability to estimate a sampling error for the survey, together with an uncomplicated questionnaire requiring only yes or no answers, severely limited the kinds of statistical analysis which could be performed on the data. However, the dichotomous nominal variables (i.e., yes-or-no answers without provision for a graded response) which comprised the vast majority of the survey questions were treated as special cases of interval scales as suggested by Rosenberg (1968) and Hyman (1955). Although the data analysis was not limited to simple descriptive statistics, any summary assertions about the level of services available to AADD persons in Region V would require a standard of comparison, namely, a comprehensive census of a sufficiently large and representative population of AADD persons. As mentioned, this was not available. This, in addition to the large amount of missing data in the responses, dictated that frequency distributions and other simple descriptive statistics form the main body of the analysis. However, simple correlations, analysis of variance, and chi square values were also computed where suggested by the descriptive breakdown of the data. Only those tests which were significant at the $p<.05$ level and above will be reported here, unless the lack of observed variance helps to clarify the findings.

Definitions

There is a fairly widespread agreement that aging is a life-long process of growth, development and deterioration which includes biological, psychological and physiological domains (Segal, 1978; Thomas, 1978). However, there is little agreement as to when an individual becomes aged. Different cutoff points have been used, depending on the biases of the researchers and availability of data, in almost all of the studies which have looked at the general area of older handicapped persons. Hanf and Kieter (1978) used two different ages, 21 and 41, in their study; Hitzing

(1978) used 40; Gordon (1977) used age 16. This project elected to use age 35 as the cutoff point for the survey. The Bureau of the Census utilizes ages 35-54 as one of its age brackets so that general population figures were readily available for age 35+. The project also adopted the brackets 55-64 and 65+ from the Bureau of the Census to obtain information from agencies.

FINDINGS

Agencies Serving AADD Persons

The agencies surveyed were assigned to one of six defined categories to facilitate data analysis. Table 2 shows that public agencies and nursing homes formed the largest cells of the sample. While most of the categories are self-explanatory, the definitions of private and consumer agencies need some elaboration. Private agencies were voluntarily rather than tax supported. Examples of such private agencies are Planned Parenthood, Goodwill, Catholic Social Services, and YMCA/YWCA. Consumer agencies included Associations for Retarded Citizens, senior clubs, United Cerebral Palsy, and Citizens for Better Care.

Table 2

Service to AADD Persons by Agency Type

AGENCY TYPE	# OF RESPONDENTS	# REPORTING SERVICES	% OF RESPONDENTS SERVING
Public	127	81	64
Private	29	19	66
Consumer	22	18	82
Nursing	94	53	56
Pub. Sch.	22	3	14
Col./Univ.	31	8	26
TOTAL	325	182	56

Overall, 182 of the 325 respondents, or 56%, reported that they were providing services for AADD persons as defined by the project. The variance in the frequency with which individual agency types reported serving AADD persons was statistically significant, ranging from a high of 82% reported by consumer agencies to a low of 14% reported by public schools. Analysis of variance indicated that this difference in frequency of service by agency type was significant with $p<.01$. The chi square test of independence also found this difference to be significant with $p<.01$.

A state-by-state analysis of the data revealed no statistically significant variance among states in the frequency with which services were provided to AADD persons. Additional analysis revealed that, while across the region the type of agency was significant in determining whether service was being provided, type of agency was not significant within all individual states. For example, type of agency was not a significant factor in either Minnesota or Illinois, but for different reasons. In Minnesota virtually all agencies appeared to be providing at least some services, while in Illinois, with the exception of public and consumer agencies, none of the agencies appeared to be offering a great deal of service (see Table 3).

Table 3

Service Provided by Agencies within States

AGENCY TYPE	MICH	WISC	ILL	MINN	IND	OHIO	REGION V
Public	57%	65%	69%	60%	67%	67%	63%
Private	86%	80%	0%	100%	50%	56%	66%
Consumer	80%	50%	100%	67%	100%	100%	82%
Nursing	59%	33%	42%	77%	75%	63%	57%
Pub. Sch.	0%	14%	0%	33%	0%	33%	14%
Col./Univ.	40%	33%	0%	25%	20%	20%	25%
TOTAL	57%	51%	46%	62%	55%	58%	56%

Demographics of AADD Persons Reported Served

While the average percentage of agencies who reported they were serving AADD persons (56%) may initially seem impressive, only 57% of these agencies were able to specify how many persons they were serving (see Table 4). Among those able to report on the number of AADD persons served, only 55% were able to provide client information by age and only 51% were able to provide client information by disability type (see Tables 5 & 6).

There were significant differences among the types of agencies reporting. Ability to provide information as to the total number of AADD persons served ranged from a high of 82% for nursing homes to a low of 42% for public and private agencies. Ability to report by age ranged from a high of 82% for nursing homes to a low of 33% for public schools (Table 5). Similarly, ability to report by disability type ranged from a high of 84% for nursing homes to a low of 32% for private agencies (Table 6).

Table 4

Agencies Able to Provide Number of AADD Persons Served

AGENCY TYPE	YES	NO
Public	42%	58%
Private	42%	58%
Consumer	67%	33%
Nursing	82%	18%
Pub. Sch.	67%	33%
Col./Univ.	50%	50%
TOTAL	57%	53%

Chi Square = 24.256 DF = 6

Level of Significance = .0005

Table 5

Agencies Able to Provide Information by Age

AGENCY TYPE	YES	NO
Public	38%	62%
Private	42%	58%
Consumer	67%	33%
Nursing	82%	18%
Pub. Sch.	33%	67%
Col./Univ.	50%	50%
TOTAL	55%	45%

Chi Square = 28.269 DF = 6

Level of Significance = .0001

Table 6

Agencies Able to Provide Information by Disability Type

AGENCY TYPE	YES	NO
Public	33%	67%
Private	32%	68%
Consumer	56%	44%
Nursing	84%	16%
Pub. Sch.	33%	67%
Col./Univ.	50%	50%
TOTAL	51%	49%

Chi Square = 37.115 DF = 6

Level of Significance = .0001

The overall inability of agencies from all states to provide even minimal demographic information on the AADD persons reported served raises at least two questions. The first has to do with the nature of record-keeping. Hanf and Keiter (1978) reported that in Oregon "little ordered, organized or standardized knowledge was available at governmental or service-provider levels." This statement apparently holds true in Region V, [illegible]2% of the agencies offering service reported they did not maintain records by the categories requested and 15% felt the categories were not applicable to their agency. While it is understandable that public schools, which do not usually serve the age range included in the survey, would be unable to provide the information requested, the almost universal inability of the other agencies to provide demographic information is difficult to account for.

This is especially true for public agencies which are mandated by federal law to maintain records by at least disability type. When it is further considered that 35% of the agencies indicated they were receiving federal funding, one has to wonder how many of the agencies have realized the implications of Sections 503 and 504 of the Rehabilitation Act of 1973 (P.L. 93-112) or P.L. 94-103, The Developmentally Disabled Assistance and Bill of Rights Act of 1975. One must also wonder how state DD councils are able to generate the data found in their state plans.

Hanf and Keiter (1978) also noted that "Planners tend to rely on statistical estimates of population magnitude derived from a procedure reported in Stevens and Heber (1952)." This procedure yields a 3% prevalence rate if applied equally across the states. But how accurate is an estimate derived over twenty-five years ago, and is a general population estimate appropriate in the case of AADD persons who as a group are at least suspected of having shorter life expectancies than the general population? Besides, no two states within Region V appeared to be using the same formula, which make interstate comparisons difficult at best.

Are there actually any AADD persons out there? Is anyone actually being served? Although agencies able to furnish figures indicated that 8,925 AADD persons were being served, this figure cannot be assumed to be a non-duplicated count. Of this number, public agencies accounted for 66%

of those served and public schools and colleges/universities each accounted for approximately 1% of those reported served (see Table 7).

Table 7

Number of AADD Persons Reported Served by Agency Type

AGENCY TYPE	TOTAL AADD	% OF TOTAL
Public	5,854	66%
Private	1,347	15%
Consumer	606	7%
Nursing	937	11%
Pub. Sch.	38	1%
Col./Univ.	39	1%
TOTAL	8,925	100%

The best available estimate indicates that the total population of the area surveyed (HEW Region V) is 19,133,000 (Statistical Abstracts of U.S. 1976). The same source estimates that 41.5%, or 7,940,195 , of this population are 35 or older. Using the 4.3% prevalence rate for DD suggested by Hammer & Richman (1975), 341,428 persons aged 35+ in the area surveyed could be expected to have a developmental disability. If we assume that all agencies who said they were providing services to AADD persons were providing service at the same rate, and if the percentage of agencies providing service among non-respondents were assumed to be the same as that of respondents, then the total number of AADD persons presently receiving service in the sample area would be 43,774 (calculations in Appendix B). If these assumptions are accepted, then only 12.8% of the potentially AADD persons in the sample area were receiving service.

Thus, as earlier suggested, AADD persons really do tend to form an "invisible client" population (Dickerson, et al., 1974). Either that, or, as suggested by Tarjan, et al. (1973), the percentages used to estimate prevalence are too high.

Number of Clients Served

When the number of AADD persons reported served is examined by age range, two factors become immediately obvious (see Table 8). The first is that agencies were better able to provide information on older clients. This was especially true for public agencies (primarily Social Security Administrations) and nursing homes where in both cases age 65 was a criterion for eligibility.

The second factor is that proportionally fewer individuals were being served in the 55 to 64 age range. While the discrepancy might be accounted for by the unequal intervals in the age ranges, something else appears to have been at work. In fact, agencies who replied to the age questions often included individuals under the age of 35 in the age range 35-54 so that this category was over-reported and actually contained individuals from age 1 to age 54. Because of these issues the greatest number of AADD persons reported served would be expected to fall in the 35 to 54 age range. However, as shown in Table 8, this was not the case.

Table 8

Number of AADD Persons Reported Served by Age Range

AGE RANGE	TOTAL SERVED	% OF TOTAL
35-54	3,257	39%
55-64	1,485	18%
65+	3,578	43%
TOTAL	8,320*	100%

*: Total < 8,925 due to inability of some agencies to provide information by age

Approximately 95% of the adult DD population simply disappears from agency roles once they complete public school. While [illegible]ordon (1978) has suggested, somewhat facetiously, that perhaps special education really does cure developmental disabilities, it seems more likely that once an AADD person completes public school, no agencies have a vested interest in them until they reach age 65. Hanf and Keiter (1978) found that among AADD persons diagnosed as CP or MR, 33% of those known between age 21 and 40 disappeared between age 41 and 60. Further, they found that only 17% of persons with CP and 50% of persons with MR remain after age 61.

It is also relevant to note here that much of the data provided by public agencies was only available for institutionalized individuals which further suggests that if individuals have somehow managed to escape institutionalization throughout their schooling, they will not appear on anyone's rolls again until they apply for disability payments, or are admitted to a home. This observation tends to be supported by a Report to the Congress (HRD-77-70, 1977) which indicated that 60% of the disabled elderly are taken care of in their homes by family and/or close friends.

Number of Clients Served by Disability Type

As Table 9 indicates, of the 182 agencies who reported serving AADD persons, only 92 agencies or 51% could provide a primary diagnosis of their client's disability. Ability to provide diagnostic data ranged from a low of 5% for public schools to a high of 47% for nursing homes. Nursing homes might be expected to do more complete diagnostic workups of their residents, but Hitzing, et al. (1978) found that nursing home staff members tended to identify some residents as mentally retarded without official diagnosis suggesting that perhaps the FLK method of diagnosis once so common in public schools lingers on. (Funny looking kid, or in this case, funny looking person.) From state to state the ability to provide diagnostic data ranged from a low of 39% in Indiana to a high of 65% in Illinois.

Table 9

Agencies Able to Provide Information by Primary Diagnosis

	Total Serving	PUB	PRI	CON	NURS	PUBSCH	COL/U	Number Providing Diag.	% of Agencies Able to Provide Diag.
Total Serving	182	127	29	22	94	22	31	--	—
MICH	49	9	1	5	7	--	2	24	49%
WISC	28	5	2	1	3	--	1	12	43%
ILL	20	4	--	1	8	--	—	13	65%
MINN	28	2	—	1	13	--	--	13	65%
IND	23	2	1	1	5	—	--	9	30%
OHIO	33	5	2	1	8	1	1	18	55%
REGION	182	27	6	10	44	1	4	92	51%
% of Total Providing Diag.		21%	21%	45%	47%	5%	13%	—	—

Table 10 indicates that agencies provided primary diagnoses for a total of 6,931 AADD persons, or 78% of the total number of AADD persons reported served. Mental retardation was the primary diagnosis most often reported (64%). However, as with the total number of AADD persons served, these figures cannot be assumed to be an unduplicated count since there is disability overlap as well as agency overlap. Hammer and Richman (1975b) estimated that 2/3 of persons with a primary diagnosis of cerebral palsy and 20-30% of those diagnosed as epileptic also exhibit some degree of mental retardation. Hanf and Keiter (1978) also reported that institutionalized AADD persons with a primary diagnosis of CP were likely to have a secondary diagnosis. Stokes (1978) pointed out that if one considers only IQ, then 80% of all autistic persons would fall into the MR range.

Table 10

Total Number of AADD Persons Reported Served by Disability Type

DISABILITY TYPE	# REPORTED SERVED	% OF TOTAL
Epilepsy	351	5%
Cerebral Palsy	216	3%
Autism	246	4%
Mental Retardation	4,464	64%
Multiple Handicaps	1,654	24%
TOTAL	6,831	100%

Using census information and the prevalence rates suggested by Hammer and Richman (1975b), Table 11 shows that if the numbers reported are assumed to be generally accurate, then the percentages of AADD persons by disability type presently being served within Region V range from [illegible]w of < 1% for those with epilepsy to a high of 19% for those with autism as a primary diagnosis. These figures appear to be roughly in keeping with the overall estimate that 12.8% of the potential AADD persons in the region are presently receiving service.

Agencies seemed more able to report age than disability type, and this appears to be the most important factor in determining who was served (Davis and Onyemelukwe, 1977).

Table 11

% of Potentially AADD Persons Reported Served by Disability Type*

DISABILITY TYPE	POTENTIAL # OF DD PERSONS BY DISABILITY TYPE	# REPORTED SERVED	% OF TOTAL
Epilepsy	64,633	351	< 1%
Cerebral Palsy	4,847	216	4%
Autism**	1,292	246	19%
Mental Retardation	96,950	4,464	5%

*: Using 3,231,659 as the base figure for persons 35+ and prevalence rates of 2%, .15%, .04% and 3% respectively

**: The number of autistic persons is felt to be inflated because an institute for autistic persons found its way into the sample accounting for 117 of those reported, and because of the general tendency to apply the label of autism to non-verbal and/or catatonic individuals.

Finally, 48 or 15% of the agencies serving AADD persons reported having identified 11,173 AADD persons eligible for services but not presently being served. Consumer agencies (23%) were most likely and public schools and colleges/universities (0%) were the least likely to have identified unserved clients. Definitional issues aside, it is hard to imagine that anyone is really looking very hard if only 12.8% of the potential AADD persons in Region V are presently being served.

Services Provided

Based on professional practice and the service areas mandated by section 102-5(M) of The Developmentally Disabled Assistance and Bill of Rights Act of 1975 (P.L. 94-103), the project chose 18 services plus "other" to include in the questionnaire. Table 12 shows the complete breakdown of services offered by agencies in order of reported frequency.

The five services most frequently reported by agencies were: 1) information/referral (36%); 2) adult activities/recreation (30%);

3) transportation (24%); 4) medical treatment (23%); and 5) staff development (21%).

These figures represent quantity, not quality, a separate issue addressed by Dickerson, et al. (1974) and more recently by Hitzing, et al. (1978).

Table 12

Services Provided by Agencies

SERVICE	N = 27 PUBLIC		N = 25 PRIVATE		N = 22 CONSUMER		N = 93 NURSING		N = 22 PUB.SCH.		N = 32 COL./U.		N = 325 TOTAL	
	#	%	#	%	#	%	#	%	#	%	#	%	#	%
Info/Refer	59	46	11	38	15	68	27	29	2	9	3	9	117	36
Adult Actv	29	23	7	24	12	55	45	48	2	9	0	0	95	30
Transporta	33	26	7	24	9	41	28	30	0	0	0	0	77	24
Med Trtmnt	18	14	10	34	0	0	44	47	0	0	0	0	72	23
Staff Devl	20	17	7	24	7	32	32	34	1	5	1	3	68	21
Counseling	26	20	5	17	8	36	21	23	0	0	2	6	62	19
Diagnostics	20	16	6	21	9	41	23	25	1	5	2	6	61	19
Education	22	17	6	21	8	36	12	13	2	9	7	22	57	18
Advocacy	21	17	4	14	6	27	16	17	0	0	1	3	48	15
Other Svcs	25	20	5	17	8	36	65	68	0	0	3	9	47	15
InHome Svcs	25	20	4	14	1	5	13	14	0	0	0	0	43	13
Dent Trtmnt	11	9	4	14	1	5	26	28	0	0	0	0	42	13
Incm Maint	24	19	1	3	0	0	16	17	0	0	0	0	41	13
Other Resid	11	9	2	7	5	23	22	24	0	0	0	0	40	13
Voca Trng	12	9	3	10	8	36	6	6	2	9	1	3	32	10
Shelt Emply	12	9	2	7	8	36	8	9	0	0	0	0	30	9
Guardianshp	8	6	1	3	0	0	11	12	0	0	0	0	20	7
Legal Svcs	7	6	1	3	3	14	6	6	0	0	0	0	17	5
Foster Care	8	6	1	3	0	0	2	2	0	0	0	0	11	3

Foster care (3%) and legal services (5%) were the two services least frequently provided for AADD persons. As might be expected, agency type was significant in some instances in determining what services were being provided (see Table 13)[5]. Two of the five services most frequently provided fell into the category of indirect service (information/referral, staff development) and were therefore possibly of less benefit to AADD persons. Citing Wolfensberger, Pezzoli (1978) has pointed out that the role of volunteer agencies has evolved into one of client advocate so that most consumer agencies are no longer providing direct service.

Of the three direct services most frequently provided, adult activities and medical treatment were most likely to be provided by nursing homes and transportation was most likely to be provided by a public agency. While nursing homes only accounted for 11% of the total AADD persons reported served, they accounted for 61% of the medical treatment (44 agencies out of 72), 47% of the adult activities (45 agencies out of 95), and 36% of the transportation (28 agencies out of 77). Before planners and policymakers decide to build more nursing homes, however, they should consult Dickerson, et al. (1974) and Hitzing, et al. (1978) who found that many AADD persons residing in nursing homes were inappropriately placed and that the quality of care was questionable at best.

Unmet Needs

Overall only 24% of the agencies identified unmet needs of AADD persons. Consumer agencies (45%) were the most likely to identify unmet needs (see Table 14). Transportation and housing were the most frequently reported unmet needs, followed closely by adult activities.

Table 15 shows that agencies in Michigan were most likely to have identified unmet needs, and that agencies in Indiana were least likely to have done so.

Table 13

Analysis of Variance of Services Offered Controlled for Agency Type

SERVICE	LEVEL OF SIGNIFICANCE	AGENCY TYPE MOST LIKELY TO PROVIDE	AGENCY TYPE LEAST LIKELY TO PROVIDE
Info/Refer	.01	Consumer	Col./Univ.
Adult Actv	.01	Nursing	Col./Univ.
Transporta	.05	Nursing	Pub.Sch.; Col./Univ.
Med Trtmnt	.01	Nursing	Pub.Sch.; Col./Univ.
Staff Devl	.01	Nursing	Col./Univ.; Public
Counseling	—	Consumer	Pub.Sch.
Diagnostics	—	Consumer	Col./Univ.
Advocacy	—	Consumer	Pub.Sch.
Other Svcs	—	Consumer	Pub.Sch.
InHome Svcs	—	Public	Pub.Sch.; Col./Univ.
Dent Trtmnt	.01	Nursing	Pub.Sch.; Col./Univ.
Incm Maint	.01	Public	Consumer; Pub.Sch.; Col./Univ.
Other Resid	.01	Nursing	Pub.Sch.; Col./Univ.
Voca Trng	.05	Pub.Sch.	Col./Univ.
Shelt Emply	.05	Consumer	Pub.Sch.; Col./Univ.
Guardianshp	.05	Nursing	Consumer; Pub.Sch.; Col./Univ.
Legal Svcs	—	Consumer	Pub.Sch.; Col./Univ.
Foster Care	—	Public	Consumer; Pub.Sch.; Col./Univ.

Table 14

Agencies Identifying Unmet Needs by Agency Type

AGENCY TYPE	IDENTIFYING UNMET NEEDS #	%
Public	40	31
Private	10	34
Consumer	10	45
Nursing	17	18
Pub. Sch.	1	5
Col./Univ.	2	6
TOTAL	80	24

Table 15

Agencies Identifying Unmet Needs by State

	MICH	WISC	ILL	MINN	IND	OHIO	REGION V
% Identifying Unmet Needs:	29%	27%	20%	27%	11%	27%	24%

The reluctance of agencies to identify unmet needs of AADD persons was somewhat surprising in light of the clear consensus among such researchers as Gordon (1977), Hamilton and Betts (1977), White House Conference on Handicapped Individuals (1977), Ross (1977), Murphy (1978), Benson (1978), and Hitzing, et al. (1978) that vocational training and employment are needed more than housing and transportation, and certainly more than adult activities.

Obstacles to Service

Agencies, as expected, indicated that lack of adequate funding (53%) was the greatest obstacle to service delivery. Overall, the obstacles to service fell into three semi-distinct categories: resources, attitudes, and training. Lack of resources (money [53%], transportation [41%], supportive services [32%], and staff [23%]) were most often listed as obstacles, followed by training (staff training [24%], finding and maintaining staff [22%], IEP/IHP [19%], and certification [9%]), and attitude (community attitude [24%], client attitude [12%], severity of handicap [17%], and other problems [16%]). It must be noted here that "other problems" was included under attitude because the most frequently cited other problem was "lack of interest in serving this population." While in some cases the client population of an agency was defined and/or limited by the enabling legislation which created the agency, in others, who was served was completely at the discretion of agency personnel so that attitude must definitely be considered as a factor.

In general, those agencies providing direct service (i.e., nursing homes) were more likely to cite problems related to staff training and keeping staff than were agencies providing indirect service. This is consistent with the nearly universal problem of nursing homes in maintaining line personnel in low esteem jobs with little or no opportunity for advancement. On the other hand, agencies providing indirect services, especially those receiving special project funding, reported virtually no problems in finding or maintaining qualified staff.

DISCUSSION

As stated in the introduction, the most significant finding of this survey is that AADD persons continue to be "invisible" as a specialized client group. Dickerson et al. (1974) has pointed out the "double jeopardy" of being old and disabled in a society which devalues and denies both. Elsewhere in this volume Levinthal raises the notion of "triple jeopardy" which must be considered in working with the AADD populations because a significant number of AADD persons (91% in Chicago) also happen to be poor (Hamilton & Betts, 1977). This notion was further supported by Davis and Onyamelukwe (1977) who found that 31.8% of all persons age sixty-five or older were below the poverty level and that the rate was worse for handicapped persons. Finally, the notion of "triple jeopardy" is also supported by an estimate from the National Clearinghouse on Aging (1978) that 10.4% of the non-institutionalized population, age sixty-five and older, of Region V were below the poverty level in 1975. As with the previous figure, it would be safe to assume that the percentage of handicapped persons sixty-five or older who are below the poverty level is greater.

Attitude

Attitude must also be considered when looking for reasons why AADD persons remain invisible to service providers. Hitzing, et al. (1978) have pointed out that five groups have historically been mistreated in the United States: prisoners, children, mentally ill, mentally retarded, and elderly persons. I think poor people could safely be added to the list along with ethnic and racial minorities. Pezzoli (1978) has stated:

> Mental retardation and old age are both handicaps, in part because of social devaluation. The reasons for our contempt, fear and devaluation of both the mentally retarded and the aged (in spite of the fact that only early death prevents us all from eventually being aged) defy rational justification but call for study of--and perhaps mark for elimination--this dark side of our character. (p.204)

Pezzoli goes on to point out the results of this attitude:

> The two groups thus share many of the same problems of societal indifference, stinginess, and contempt, mixed with equally dehumanizing pity, patronization, and--most annoyingly--a

> tendency to treat both retarded and aged persons as children. We tend to talk to both the retarded and the very old in the same manner we do to children, foreign visitors and TV Indians: in loud voices using simple words and with a kind of melody to our phrases. (p.206)

Given the psychological barriers we have created to keep us at a safe distance from the "different ones," it is little wonder that the field of AADD is so clouded (Becker, 1973). Even among the alleged experts in the field there is little agreement on such basic issues as definitions of aging and aged. Davis and Onyemelukwe (1977) raised the definitional issue at The White House Conference on Handicapped Individuals:

> There is a general consensus that old age is the last stage of human development, but there is little agreement as to the exact age at which this final stage begins, or the actual physical signs that indicate its onset. (p. 459)

This lack of clear definition of the potential population to be served is a major obstacle to service. The Education of All Handicapped Children Act of 1975 paved the way for comprehensive services to the school age population, but thus far The Developmentally Disabled Assistance and Bill of Rights Act of 1975, Sections 503 and 504 of The Rehabilitation Act of 1973, and The Older Americans Act of 1965 have not resulted in the same degree of comprehensive services to AADD persons. The categorical nature and overlapping provisions of these acts will continue to be obstacles to implementation until the State DD Councils begin to exercise their mandate to coordinate service delivery within states.

Perhaps what is needed is a less arbitrary and more philosophical definition of aging. Michel Philibert (1978) has suggested that: "Aging is a path through truth and suffering to death. Hopefully, the moment of truth comes before the moment of death."

Like it or not, we are all members of an aging society—a fact which gets more difficult to deny as the mean age of citizens in the United States continues to rise. In the last ten years the percentage of elderly persons in the U.S. has increased 40.3% while the total population has only increased 23.9%. Cohen (1978) estimated that the number of persons over sixty-five will double by the year 2000.

Perhaps legislators, who are themselves growing older, are more responsive to the new interest in gerontology than they are to the movement to deinstitutionalize handicapped persons. Certainly few advances in service delivery have been made for AADD persons despite increased attention and legal mandates (Gordon, 1978). While each of us cannot forever deny the phenomena of aging, we can continue to screen ourselves from disability. Deinstitutionalization has failed to integrate the fewer than 10% of the AADD persons formerly housed in institutions into the community. Instead, segregated half-way houses in the least desirable sections of our urban centers house the moderately disabled persons, and more severely disabled persons are retained in institutions or inappropriately placed in nursing homes or in the community (Dickerson, 1974; Hitzing, 1978). This is our untouchable population.

No general indictment of nursing homes is intended; many of them are doing an excellent job of providing a much needed service. However, nursing homes do not usually have staff members who are trained to provide for the specialized needs of AADD persons, and often do not even understand that some of their residents are developmentally rather than physically disabled and so could possibly benefit from a less restrictive environment. Zigler and Balla (1977) argue that AADD persons housed in closed settings learn no skills and tend to lose the skills they had previously acquired.

However, AADD persons confined to institutions and nursing homes are not that much worse off than their cohorts placed in the community without skill development programs. Very few educational or vocational programs are offered for older DD persons and even fewer sheltered employment programs exist. Hamilton and Betts (1977) found that less than 9% of the AADD persons in Chicago were employed, and Ross (1977) pointed out that, despite increased funds, the enrollment of handicapped persons in vocational educational classes has been decreasing (nor was this phenomenon accounted for by mainstreaming). In fact, rather than vocational training for independence, AADD persons receive SSI and disability payments which tend to make them more dependent and to reinforce the notion that they are surplus citizens who should be kept out of the labor force. These "surplus citizens," having no societal niche, have no recourse except to become invisible. Gordon (1978) has pointed out that once AADD persons leave school they "no longer exist as a member of a significant consumer group requiring specialized services." Traditional advocacy methods are not available to AADD persons because advocacy for equal educational opportunity and equal rights has relied on the "equal protection of law" clause of the Constitution of the United States. In the case of AADD persons, such an argument would only result in equally bad treatment because only the very rich, or those able to work most of their lives in order to build a pension fund, are able to tolerate growing old in this society. As we have already seen, few AADD persons have had a chance to work, and even fewer are wealthy. Thus, most become the victims of "triple jeopardy."

Educational programs for AADD persons were provided by only 14% of the public schools and 26% of the colleges/universities reporting, although nearly all probably had adult or continuing education programs for the "normal" population. Therefore, looking to past court rulings on equal educational opportunity, be it desegregation or special education, it would seem that once schools and colleges provide adult education and/or continuing education for any adult, they have an obligation to provide it equally for all. In other words, "equal protection" might be interpreted to mean that local school districts could have an obligation to extend special education services into adult education programs, even though such services are not specified in most mandatory special education laws.

Similarly, colleges and universities (large consumers of federal dollars) probably could do a better job of seeking out handicapped students through affirmative action programs as suggested by Section 503 of The Rehabilitation Act of 1975. Here again administrative attitudes probably combine with lack of consumer awareness to insure that education is preserved for the best, the brightest, and the most beautiful.

Despite increased awareness and new mandates for service most recently emphasized by The White House Conference (1977), there has been little growth in services to AADD persons. General ignorance of the field is probably the largest reason no new services have come into being and that existing services have not been better coordinated. Nursing homes, the agencies most often providing direct service to AADD persons, reported that finding, training, and maintaining qualified staff was the chief obstacle to serving AADD persons. Gordon (1977) noted that 53% of the agencies surveyed felt that new careers were needed in developmental disabilities and 76% felt that current professional training was only poor to fair. Thurman, elsewhere in this volume, notes that virtually none of The University Affiliated Facilities (UAFs), the entities created by the DD Act to train professionals from various disciplines in developmental disabilities, reported they were presently providing training in AADD nor did many UAF's indicate interest in doing so in the future.

Monies to train staff are available through Title XX of the Social Security Act, but most agencies would have difficulty meeting all of the affirmative action and non-discriminatory provisions of related Acts. For instance, the Act requires individual habilitation plans (IHPs) for each client served. Although few of the agencies surveyed reported that IHP's were a problem, Hitzing (1978) found that none of the nursing homes surveyed in Nebraska had IHPs. This probably explains why so few agencies thought they were a problem.

The future, while grim, does not appear to be completely hopeless. Hofmeister and Gallery (1978) have pointed out that appropriate training packages already exist which only need to be identified, adopted, and funded for use with staff working with AADD persons. For this to happen, State DD Councils will need to do a better job of increasing the awareness of service agency staff of the needs of AADD persons. DD councils should also coordinate services at the state level to meet these needs. Both are much easier said than done. The third thing that needs to happen is that University Affiliated Facilities must begin to train professional and paraprofessional personnel to meet the needs of older DD persons. Unfortunately, the attitude of UAF administrators toward AADD persons is about on a par with that of the general population, so that nothing is likely to happen in the near future on a voluntary basis. Thus we are left with the hope that personnel trained in gerontology and personnel trained in disability will somehow come together in voluntary networks and begin to work together to develop mutual training programs in AADD. But the hope for voluntary action is slight. When asked what new programs they would provide for AADD persons if adequate monies and staff were available, the most frequent reply of agencies was "none," closely followed by "more of the same," which are really the same answer.

One additional obstacle must be mentioned: the problem of dealing with a second-party client. Parents, relatives, close friends and/or legal guardians are the primary care-givers for AADD persons. Hofmeister and Gallery (1978, p. 94) cite Kriger (1975) and Nihira and Nihira (1975) to support their assertion that "caretaker" is perhaps a better descriptor of the role played by these individuals: "Unfortunately, the caretaker is often ill-prepared for this role, having little or no training." To the extent that these second-party clients have been frustrated in past efforts to get services from the system, and to the extent AADD persons have been debilitated by the system, their attitude of distrust for and avoidance of the system is understandable. New hope can only be rekindled when the system stops being a greater problem than the one it was created to serve. The re-education of the primary care-givers is the necessary first step in building a power base to advocate for AADD persons. Perhaps what is needed is a kind of alumni association for parents and guardians of old special education students. Going strictly by educational definitions, such an organization would at least put to rest all questions about the existence of AADD persons.

SUMMARY

The AADD client is just as invisible in Region V in 1978 as in 1974.

Few agencies are aware of the existence, let alone the needs of AADD persons. Only 56% of the agencies responding reported serving AADD persons. The services which do exist are poorly coordinated. Adequate records are not maintained to document the services provided. Only 24% of the agencies surveyed could identify unmet needs of AADD persons, and only 15% could identify unserved clients.

The services most often provided (information/referral, adult activities, medical treatment, transportation and staff development) were mostly of an indirect nature; most direct services were provided by nursing homes. The primary obstacles to service were lack of resources, negative attitudes, and lack of training in the field. Transportation and housing were identified as the greatest unmet needs of AADD persons and, while lack of adequate funding was cited by 53% of the agencies as an obstacle to service delivery, most agencies said they would do nothing new if adequate funds were available.

While many caregivers would like to believe that we are at a point in time when we can begin to accept both aging and individual differences, the apparent apathy reported here seems to suggest that even in 1978, helping professionals continue to deny, ignore or forget older disabled persons. Thus, to paraphrase Philibert (1978), it would seem that when it comes to providing community services for AADD persons, we may be closer to the moment of death than the moment of truth.

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ILLINOIS: FACTORS AFFECTING THE RESPONSE OF HUMAN SERVICE ORGANIZATIONS TO AADD CLIENTS

by

Salvador Lopez

The major obstacle impeding the provision of services at this point in time is the lack of knowledge about who the aging and aged, developmentally disabled person is and what his/her needs are. The stage of development of a service delivery system for this person can be characterized as a nascent one; that is, the process of defining the target population is still going on (Kriger, 1975). Movement from the present stage to another more advanced one requires the acquisition of more knowledge about the nature of the client's problem, about the service and treatment technologies, and about pressures on the organization's delivery system to perform adequately.

It is interesting that in the small amount of literature which has been written about the AADD population no mention has been made about the central role played by human service organizations. The problems involved in the provision of services for the AADD population will be viewed in this paper from the perspective of the human service organization as an actor in the total process.

HUMAN SERVICE ORGANIZATIONS AND THE AADD CLIENT

Research on human service organizations has found that the service delivery system is affected by factors that are internal or external to the organization (Hasenfeld & English, 1974). In this research human service organizations are conceptualized as dynamic living systems which, like any living organism, must respond and adapt to their internal and external environments (Georgopolous, 1972). If these environmental factors are known, then certain adaptive behaviors can be expected.

For example, Scott (1974) found in his study of programs for blind disabled persons that organizations adapted service behaviors--and this is a frequent maladaptive outcome--which were quite in contrast with their original intent. These organizations began to limit their selection of clients to those who were very likely to succeed in their programs and who possessed attributes which society valued, such as youth, middle class educational and social familial background, etc. If the organizations were successful with their clients, they would continue to receive funding--and thus survive at the expense of the needs of the unselected clients. It is important, therefore, Hasenfeld (1974) concluded, that the factors which shape the organizations are understood and the knowledge used so that organizations pursue "norms of rationality," which means that they meet the needs of the clients rather than their own or those of society.

Although there are a multiplicity of factors which have been found to affect organizational behavior, this study will limit its concern to a few salient factors.

First, the most obvious factor determining the services a client population receives is knowledge of who the client is and the nature of his problem. The less that is known about the client, the fewer services the professional providers will be able to develop for him.

A second factor is the state of development of the treatment technology which is dependent in turn on the knowledge of the client's problem and needs (Hasenfeld & English, 1974). If this knowledge is still in an early developmental stage, then the technology will reflect this condition, and the services being provided by organizations will reflect it as well. For example, Perrow (1965) found that a mental hospital emphasized custodial care goals rather than treatment because it had no rehabilitative technology that would work in that setting. In addition, the more indeterminant the needs of the client, such as social or psychological needs as opposed to a more precise physical need, such as a medical operation for which a fairly determinant prescribed technology exists, the more uncertain will be the delivery of such indeterminant services (Hasenfeld, 1974).

A third factor which affects the service delivery system is external pressure or lack of pressure exerted by such external forces as the community, the client being served, or social or legal groups. The local community can exert pressure on organizations to create and develop programs for its clients (witness local school districts' haste to begin bilingual education programs, not because of the national legislation, but because of community demands) or to inhibit innovative program development (Ohlin, 1974) because the community finds it to its dislike. The client population can have similar effects if they are active and have a power base. Bechill (1978), in his discussion of factors influencing the formation of public policy, cites the example of the elderly population's successful campaign to pass federal and state legislation which favors their situation. Beck and Marvit (1977), on the other hand, point to the negative effects on mental health services if the clients are powerless.

Other sources of pressure are what Zald and Hair (1972) refer to as "control agents," which are various groups in society which are the definers of what organizations are to do, as well as enforcers of their performance. The following are examples of control agents:

> . . . governmental agencies that 'own' the institutional elements; professional standard-setting associations; legal institutions including courts of law; organizations affecting the legitimacy of institutional performance, such as newspapers and licensing boards; labor unions, 'umbrella' organizations made up of representatives of the institutional elements' major users or resource providers; boards of directors; and executive elites. (p. 54)

The degree of power these control agents have over the organizations' programs will, of course, determine the effects on the services they provide in terms of development, reduction, or elimination. It is therefore important for effective service delivery that external forces, at least of the positive kind, exist (Hasenfeld, 1974).

A. Present State of Services for the AADD Client

Reviewing these three factors (knowledge of the population, development of treatment technology, and external pressure) as they exist in the service delivery system for the AADD clients, we find a state of affairs which can only speak ill of what they are receiving in contrast to what they rightfully deserve.

1. Knowledge of the Client Population

The basic obstacle impeding the service delivery system for the AADD client thus far is related to the lack of clarity about the term Aging/Aged Developmentally Disabled. Thomas and Acker (1978), in their paper which sought to clarify this term, stressed the point that without a clear definition of this population the negative consequences are many: insufficient allocation of funds; inability to advocate as a group for their rights and for the types of services they desire; inadequate program planning to meet their needs. Other workers in the field agree that there is little information available about the service delivery system and demographic data (Hamilton, Betts, et al., 1977; Hanf & Keiter, 1977; Thomas & Acker, 1978). This deficiency is attributed to the lack of comprehensive data collection systems throughout the country (Thomas & Acker, 1978) and the lack of records identifying these clients. When records are available, their diagnostic accuracy is in question (Hitzing, McGee, Wood, et al., 1978; Thomas & Acker, 1978).

As for the services themselves, they too reflect the confusion that exists about the population itself. What the service needs of this client are and their order of priority are sources of debates according to Hanf & Keiter (1977). More specifically, they add that

> . . . a diversity of personal beliefs coupled with direct personal experience with AADD's seems to provide the basis for a best estimate as to the AADD's needs. (p. 1)

This notion is also confirmed by Tavis and Onyemelukwe (1977) and elaborated in the report from the White House Conference on Handicapped Individuals.

In addition, these writers stress the necessity of having a conceptual framework from which to direct their work. It is apparent, therefore, that development of programs which will meet the needs of the AADD person is hindered by the lack of knowledge and of a conceptual base from which to operate. Segal (1978) sums up this discussion:

> At the present time little is actually known about the social, psychological, economic, and medical aspects of the elderly developmentally disabled person. More research needs to be undertaken to identify and locate this group, to better determine their needs and develop services to help resolve their social problems. (p. 11)

2. State of Treatment Technology

Segal's statement brings us to the discussion of the second factor which affects the service delivery system of an organization. It is the question of what types of treatment/change technologies are needed to meet the needs of the AADD person. These technologies involve medical, rehabilitative, educational, vocational, and psychological factors. Recent studies have found that the majority of services being provided are those which meet their basic survival needs such as medical and economic needs, while the least provided are educational, vocational, and psychological services, which would help them achieve a higher level of functioning in the community--a level of which they are quite capable given the proper technologies.

Several studies which investigated the services provided by residential settings for the aging/aged mentally retarded found them to be remiss in providing services other than the survival types (Dickerson *et al*., 1974; Hitzing, McGee, Wood, *et al*., 1978). In addition, they found that additional services which were available in the community were inaccessible to those persons. Another study found that community-placed mentally retarded adults were able to learn more adaptive and normalized behaviors (Nihira & Nihira, 1975a) than in a residential setting. However, from the same study, they found that there were health, safety, and legal risks that these clients had to face in the community (Nihira & Nihira, 1975b). The researchers recommended that programs or techniques be developed for community caretakers so they could help clients learn normalizing and adaptive behaviors and avoid the inevitable risks inherent in community living. Hofmister and Gallery (1978) point out that many already existing programs in the community could be easily adapted for AADD persons. These and other studies not mentioned in this discussion indicate that, not only is there little information concerning the AADD person living in the community, but the treatment and change technologies needed to help the AADD client achieve a higher level of functioning are lacking or in an early developmental stage.

Other researchers who have investigated this same situation (Dickerson, et al., 1974; Segal, 1978; Thomas & Acker, 1978) have generally found that program development is at the same poor level as the knowledge of this population. Thomas and Acker (1978) and Segal (1977) mentioned a few innovative programs which exist in different parts of the country. However, how these can be implemented elsewhere has yet to be explored. Segal expressed a need for treatment and change technologies which would focus on other important, though not so overt, aspects of the AADD person's needs, such as

> . . . 1) the need for sexual expression; 2) the need for spiritual expression; 3) the need for personal stability; and 4) the need for opportunities to express feelings regarding death and dying. (p. 8)

Thus it is clear that the service technology has yet a long developmental road to travel before it filters down to the organizations which will use it to serve the AADD client.

3. External Pressures Affecting Service Delivery

The third major factor affecting the present and the future provision of services to the AADD client is the lack of political and legal pressures being exerted on the policies of national, state, and local human service organization structures (Bechill, 1978). Bechill argues that pressure has to be exerted on those social systems which affect public policy. He advocates that organizations interested in the AADD client must acquire adversary skills, develop coalitions which can exert pressure, and build and mobilize political support for the needs of the AADD client. This is necessary because, even though federal legislation exists (P.L. 94-103) which outlines plans for the provision of services for this population, there is no built in mechanism--to serve as control agent--which would enforce its implementation. Furthermore, there have been no Federal Court cases to date which have mandated, in an enforceable manner, that specialized services by certain agencies must be provided to this population.

Other sources of pressure on organizations to provide adequate services for the AADD client which are lacking are from the community and the client himself. Literature on the subject of the community and the AADD client reveals that the community is not even aware of their existence much less their problems or needs. Nor are the potential clients themselves exerting pressure for service. The reasons are outlined by Beck and Marvit (1977) in their paper on the mental health consumers' lack of involvement in the service delivery system: 1) the services are controlled by the providers (a control that is inherent in most public human service organizational systems); and 2) the consumers are uninformed and powerless. This being the case, Beck and Marvit argue that

> If the consumers of mental health services were informed, they would very likely demand more and better services than they are presently receiving, particularly from public agencies. (p. 4)

Though they are speaking about mental health clients, the AADD client is in similar straits. Indeed, probably worse, since the AADD clients are, because of their disabilities, more helpless.

B. Investigative Questions

Given the state of affairs that has been presented and discussed above, the survey data from Illinois, which is part of a larger study, can answer three questions derived from the literature:

A) Will the organizations exhibit behaviors which are due to the lack of definition of the population, the lack of clarity of the nature of the client's problem and his needs? The question will be answered by the agencies responses to the questions in the survey which are aimed at determining its

1. ability to identify client by age and disability;
2. ability to identify unmet needs; and
3. ability to identify clients not being served.

B) Will the types of service the organizations are providing be consistent with the treatment technology developed thus far? This question can be answered by analyzing the information obtained from the questions which seek to determine:

1. the kinds of services the organizations are providing;
2. the additional services the organization would provide if funding were available.

C) Are the organizations experiencing external pressures from the community, the client, or social control agents which might be aimed at changing the organizations' system of service delivery? This question can be answered indirectly from the responses which provide information about the organizations':

1. ability to identify client by age and disability;
2. sources of funding; and
3. the organization's perceptions of what obstacles interfere with the provision of services.

C. Survey Response Rate as a Whole and for Illinois

Of the 639 questionnaires mailed, 325 were returned completed by the cut-off date for an overall response rate of 55%. The response rates by states ranged from a high of 63% in Minnesota to a low of 47% in Illinois and Ohio. Table I provides details about responses to the survey.

Table I

Overall Survey Response Rate

State	Number Mailed	Bad Address	Number Delivered	Returned Completed	Response Rate
Michigan	149	4	145	86	59%
Wisconsin	95	6	89	55	62%
Illinois	109	11	98	46	47%
Minnesota	78	7	71	45	63%
Indiana	71	7	64	38	59%
Ohio	137	11	126	55	47%
Region V	639	46	593	325	55%

The two areas in Illinois sampled were the large metropolitan city of Chicago (pop. 6,071,000) and Champaign, a small university town (pop. 100,000). Out of the 98 questionnaires delivered to agencies in these areas, 46 (47%) were completed and returned. The numbers of agencies responding according to type were as follows: 13 public agencies, 24 nursing homes, 4 private agencies, 3 college/unversity, and 2 consumer. Of these, 9 public agencies, 9 nursing homes, and 2 consumer agencies were providing services to AADD clients. Broken down into areas, 5 public agencies, 7 nursing homes, and 2 consumer agencies were from the Chicago area, which comprised 65% of agencies providing service. Four public agencies and 2 nursing homes were from the Champaign area. Details appear in Table II.

A recent and comprehensive study of the medical and allied health services delivery systems in the Chicago area (Hamilton & Betts, 1977) estimated that the number of AADD persons living in the area was 122,000.

Using the 1.8% rate they used, we estimated the AADD population in Champaign to be 1800. These rough estimates will be used as a basis for comparing the number actually receiving services in the areas with the number not receiving them.

Table II

Agencies and No. of People Served

AGENCY TYPE	# Responding to Questionnaire	% of Sample	# Providing Services	% Providing Services of Total
Public	13	28	9	69.23
Nursing	24	52	9	37.5
Consumer	2	4.35	2	100
Private	4	8.70	0	0
College/University	3	6.52	0	
TOTAL	46		20	

RESULTS

A. Lack of Definition of the Population

1. Ability to Identify Clients

As expected, not all serving agencies were able to identify the number of clients served by age and/or disability category. Table III shows that a total of 1125 persons were identified according to age category. Public agencies accounted for 821 persons (70%), nursing homes for 259 (25.6%); and consumer for 45 (3.9%). This number is, of course, a considerable distance from the estimated AADD population of 123,800 which should live in both areas.

Table III

No. of People Receiving Services According to Age Identification

Age Categories	PUBLIC (9)		NURSING (9)		CONSUMER (2)		TOTAL (20)	
	#	%	#	%	#	%	#	%*
35 - 54	97	43.49	81	36.3	45	20	223	19.8
55 - 64	24	29.62	57	70.37	0	0	81	7.2
65 - older	700	85.26	121	14.73	0	0	821	73
TOTAL	821	70.47	259	25.66	45	3.86	1125	100

*: of Total (1125)

After calculating the number of persons being served within each age category, it was found that the highest number (73%) fell into the 65 or above category. Such information and the fact that the highest percentage of the AADD population is thought to be younger than 65 underscores the paucity of services for the under 65 population. Though this finding appears to have a logical explanation, given the large number of nursing agencies responding, it is noteworthy that the explanation is not due to that factor. Indeed, one public agency, which serves AADD clients in the Chicago area, accounts for 85.3% (700 clients) of the total in that category. Thus 6 agencies (1 public and 5 nursing), out of 13 agencies, identified 73% of the persons being served across all age categories. Seven agencies, therefore, were providing services for the remaining 27% which fell into the other two categories.

With respect to the disability categories, Table IV shows that the largest number identified was found in the MR category (344 out of a total of 510); those receiving less service were found in the autism (2), cerebral palsy (14), and epilepsy (33) categories. These discrepancies, however, do not lend themselves to interpretation due to the fact that 66% of the cerebral palsy handicapped usually fall into the MR category, and similarly 20 to 30% of epileptics are also likely to be in that category. It is important to note, however, that the total number identified (510) was considerably less than the number identified by age category (1165), though some agencies were able to include the same number in both categories. This discrepancy suggests the following question: If AADD clients were the target clients of these agencies, would they not have been able to identify the number served with some accuracy?

Table IV

No. of People Receiving Services According to Disability Category

Disability Categories	PUBLIC		NURSING		CONSUMER		TOTAL	
	#	%	#	%	#	%	#	%
Epilepsy	10	30.3	23	69.7	0	0	33	6.5
Cerebral Palsy	9	64.3	5	35.7	0	0	14	2.7
Autism	0	0	1	100	0	0	1	.02
MR	112	32.55	187	54.4	45	13.1	344	67.45
Multiple Handic.	76	64.4	42	35.6	0	0	118	23
TOTAL	207	40.6	258	50.6	45	8.8	510	100

The problem of identification becomes more apparent when the number of agencies able to identify either by age and/or disability category are grouped together. As Table V indicates, there was little difference between age category (65% of agencies) and disability category (60%). Again this information points to the possibility that perhaps agencies serve AADD clients for other reasons than those derived from the nature of their disability. If this is the case, then the service situation for this population is not a healthy one in light of Table V which indicates that those agencies (public) which are serving the greater numbers of this population were least able to identify by age (44.4%) and by disability (33.3%).

Table V

Agencies Able to Identify by Disability and Age Categories

Categories	PUBLIC #	PUBLIC %	NURSING #	NURSING %	CONSUMER #	CONSUMER %	TOTAL #	TOTAL %
Disability	3	33.3	8	88	1	50	12	60
Age	4	44.4	8	88	1	50	13	65

Table VI

Total No. Who Do Not Keep Records for One or More Reasons

	PUBLIC #	PUBLIC %	NURSING #	NURSING %	CONSUMER #	CONSUMER %
Reasons for no categories	6*	66.6	1	11.1	1	50

*: One public agency answered number 15 even though they had provided age category information. Another agency checked number 15 and 18 yet had provided an estimated number of persons being served according to DD category, which was tabulated into the total number being served.

Closer inspection of the reasons given by the agencies to explain their inability to identify by categories, (see Table VI) revealed important information. Table VII shows that there is a relationship between the type of funding an agency received and the likelihood that it would be able to identify clients by categories. For example, a significant relationship ($p < .01$) was found between agencies receiving special funding and their inability to identify clients by either category, which suggests that special funding is not designated for the target population, because funding sources usually require information about the use of their funds. In addition, a high percentage (62.5%) of agencies receiving federal funds were unable to identify their clients. This is rather high in light of the fact that Federal legislation exists which was designed to provide monies for agencies serving the population.

Table VII

Type of Funding Received and Ability to Identify Clients by Age and Disability

	N = 8 FEDERAL		N = 15 STATE		N = 3 COUNTY		N = 9 PRIVATE		N = 4 SPECIAL	
	#	%	#	%	#	%	#	%	#	%
Unable to identify	5	62.5	5	33.3	2	66.6	2	22.2	4*	100

*: $p < .01$

2. Identification of Unmet Needs and the Number of Clients Not Receiving Services

Two sets of questions were asked. The first set was concerned with the kinds of needs not being met: "Has your agency identified client needs which are not being met?" and, "If so, what are they?" The second set was concerned with the number of clients needing services: "Has your agency identified older/aged developmentally disabled clients who are currently not receiving services and should be getting them?" and, "If so, how many?" As shown in Table VIII, less than 45% of both public and nursing home agencies were able to respond to the first set of questions and provide an estimate of the number of clients needing services. As shown in Table IX, these same respondents emphasized the need for services which would help these clients support themselves and function more independently (Sheltered Employment, Vocational Classes and Adult Education). The 8 agencies that responded estimated that 401 persons were not receiving services. One consumer agency responded yes to the first question and identified two needs, but was unable to provide a number or estimate of clients needing services. The small number of agencies responding, and the small estimated number of persons who needed services, reflects the lack of awareness of the AADD population's existence beyond the clients the agencies already serve.

Table VIII

TYPE OF AGENCY	# of Agencies Identifying	%	# of DD Identified	%
Public	4	44.4	267	66.6
Nursing	4	44.4	134	33.4
TOTAL	8		401	

Less than 45% were able to identify the number of DD persons needing services.

Table IX

Number of Unmet Needs Identified by 9 of the 20 Agencies Providing Service

NEEDS	PUBLIC (N=4)	NURSING (N=4)	CONSUMER (N=1)	TOTAL
Outreach	1	0	0	1
Respite Care	1	1	0	2
Voc. Classes	0	2	0	2
Motivation	0	1	0	1
Housing	0	0	0	0
Adult Education	1	1	0	2
Accessability	0	0	1	1
Recreat. Act.	1	0	1	2
Shelt. Employ.	1	2	0	3
TOTAL UNMET NEEDS	5	7	2	14

B. State of Development of Treatment Technology

1. Types of Services Provided by Agencies

Analysis of the data on services can be approached from the perspectives created by the following questions: What are the kinds and frequency of services being provided? Are there agency differences? How does funding source affect the kind and frequency of services provided?

First, the kinds of services were divided, for purposes of analysis, into two parts: 1) the most frequently provided services across agencies, and 2) the least provided services. Table X shows that 75% of the agencies (15) were providing Information/Referral; 65% were providing Medical; 60% (12) were providing Adult Activities/Recreation; 60% were providing Dental; 60% were providing Transportation; 55% (11) were providing Diagnostic; 50% were providing Counseling and Treatment and In Home Service. It is important to note that the most commonly provided service (Information/Referral) is an indirect service, and that the other common services are of a maintenance kind, that is, services that are aimed at helping the disabled person meet his basic survival needs.

Table X

Most Frequently Provided Services Across Agencies

SERVICES	% AGENCIES
Info./Ref.	75
Medical	65
Adult Act./Rec.	60
Dental	60
Transport.	60
Diagnostic	55
Counsel./Treat.	50
In-home Serv.	50

In contrast, the list of least provided services by agencies tells another story. Table XI lists the following services: Foster Care (0%), Vocational (10%), Guardianship (15%), Sheltered Employment (20%), Legal Services (20%), and Educational Classes (25%). None of the agencies acknowledged in a space labeled "Other" any new or different program they were providing. Yet this discrepancy is understandable because many of the surveyed agencies have programs that are generally aimed at providing a particular type of service. The story that these percentages tell is that the bulk of the services which are presently being provided, though good in their contribution to the needs of the AADD population, are not directed at helping the AADD person improve skills which could enable him to function more independently in the community, such as occupational and educational training, sheltered employment, or learning adaptive social skills.

Table XI

Least Frequently Provided Services Across Agencies

SERVICES	% AGENCIES
Foster Care	0
Vocational	10
Guardianship	15
Shelt. Employ.	20
Legal Services	20
Ed. Classes	25

In considering the frequency of services provided by agency types, the two consumer agencies were not included, as it was thought that they were too few from which to derive conclusions. The two remaining types revealed an interesting contrast. As Table XII (following page) shows, nursing homes--as might be expected of 24-hour care institutions--provided the greatest number of services. What was surprising, however, was the small number of public agencies providing services and the small number of services they provided.

Table XI

Services Provided by Particular Types of Agencies

Type of Service	PUBLIC (N=9)		NURSING (N=9)		CONSUMER (N=2)		ACROSS AGENCIES (N=20)	
	#	%	#	%	#	%	#	%
Ed. Classes	2	22.2	3	33.3	0	0	5	25
Vocational	0	0	1	11.1	1	50	2	10
Shelt. Employ.	1	11.1	2	22.2	1	50	4	20
Adult. Act./Rec.	2	22.2	9	100	1	50	12	60
Info./Refer.	8	88.9	6	66.6	1	50	15	75
Counsel./Treat.	3	33.3	6	66.6	1	50	10	50
Medical	3	33.3	9	100	0	0	13	65
Diagnostic	3	33.3	7	77.7	1	50	11	55
Staff. Dev./In-Service	1	11.1	6	66.6	1	50	8	40
Dental	3	33.3	8	88.9	1	50	12	60
Transport.	5	55.6	6	66.6	1	50	12	60
Guardianship	0	0	3	33.3	0	0	3	15
Personal Adv.	3	33.3	4	44.4	0	0	7	35
Inhome Service	4	44.4	5	55.5	1	50	10	50
Legal Serv.	0	0	3	33.3	1	50	4	20
Foster Care	0	0	0	0	0	0	0	0
Other Resid. Care	1	11.1	7	77.7	1	50	9	45
Income Maint.	1	11.1	6	66.6	0	0	7	35
Other	2	22.2	1	11.1	0	0	3	15

This lack can be explained in several ways. One is that even though federal legislation and federal funds are available, many agencies may not be actively seeking such funds. The second is related to the kinds of services they provide, that is, since public agencies provide few of the services which, as already discussed above, enhance the independent functioning of the AADD person, it can be concluded and has been suggested above that many of these agencies provide services for this population, not primarily because of their handicap, but because in some general way these agencies can provide some assistance, such as welfare, social security, and mental health services.

To some extent funding source was found to be related to the types of service provided. Table XIII shows that, in general, agencies that receive state funding tended to provide considerably more services, while county and specially funded agencies provided fewer services. Federal and private funded agencies lay somewhere in between. In a few instances, there were significant relationships between a service and funding source. For example, there is a significant likelihood ($p < .01$) that state funded agencies will provide "Diagnostic" and "Other" services; while county funded agencies are likely ($p < .05$) not to provide "Dental" services and special funded agencies are likely ($p < .01$) not to provide "Medical" or "Dental" services. Federally funded agencies seem to provide the more expensive types of services.

Table XII

Types of Services Provided by Funding Source

TYPE OF SERVICE	TYPE OF FUNDING									
	Federal		State		County		Private		Special	
	#	%	#	%	#	%	#	%	#	%
20. Ed. Classes	2	25	5	33.3	0	0	2	22.2	0	0
21. Voca. Classes	1	12.5	2	13.3	0	0	2	22.2	0	0
22. Shelt. Employ.	2	25	4	26.7	0	0	3	33.3	0	0
23. Adult Act./Rec.	3	37.5	9	60	1	33.3	6	66.7	2	50
24. Info./Referral	7	87.5	12	80	3	100	6	66.7	3	75
25. Counsel./Treat.	2	25	8	53.3	2	66.7	6	66.7	1	25
26. Medical	2	25	10	66.7	1	33.3	6	66.7	0*	0
27. Diagnostic	3	37.5	10*	66.7	2	66.6	5	55.4	1	25
28. Staff Develop.	3	37.5	7	46.7	0	0	4	44.4	0	0
29. Dental	4	50	10	66.7	0+	0	7	77.8	0*	0
30. Transport.	6	75	10	66.7	1	33.3	5	55.4	2	50
31. Guardianship	0	0	2	13.3	0	0	2	22.2	0	0
32. Personal Advoc.	1	12.5	6	40	2	66.7	3	33.3	2	50
33. In-home Serv.	6	75	9	60	1	33.3	5	55.5	2	50
34. Legal Service	1	12.5	2	13.3	0	0	2	22.2	1	25
35. Foster Care	0	0	0	0	0	0	0	0	0	0
36. Oth. Res. Care	3	37.5	6	40	0	0	5	55.6	0	0
37. Income Maint.	2	25	7	46.7	0	0	3	33.3	0	0
38. Other	1	12.5	0**	0	1	33.3	0	0	1	25

*: $p <.01$ +: $p < .05$ **: $p < .01$

2. The Possibility of Providing Additional Services

A bright spot in the service situation appeared when the responses to the following question were analyzed: "If additional staff and funds were available, what other services would your agency provide to meet the needs of the older/aged developmentally disabled client?" The kinds of responses made, and the number of agencies (75%) that responded, point to a desire to develop and expand services beyond what already exists (see Table XIV). As Table XV shows, however, few agencies were interested in expanding their services to include sheltered employment, education, and vocational classes and "independent motivation". This information reinforces the need for these services which will enhance independent functioning as mentioned previously. Finally, it is interesting to note that, of the agencies that did respond to the question, one said that they did not know what they would do with added staff and funds, and another said they would not provide other services.

Table XIV

No. of Agencies Who Responded to "Additional Services" Question

PUBLIC		NURSING		CONSUMER		TOTAL	
#	%	#	%	#	%	#	%*
6+	66.6	7	77.7	2	100	15	75

*: of Total (20)

+: Two public agencies responded to the question. One added that it would not provide other services and the other that it did not know what else it would provide.

Table XV

Additional Services Provided Were Funds & Staff Available

SERVICES	# AGENCIES	SERVICES	# AGENCIES
Shelt. Employ.	3	Foster Care	1
Educational	2	Other Resid. Care.	1
Vocational Classes	2	Unsure	1
None	2	Independent Living	1
Transportation	1	More of same	1
Guardianship	1		

C. External Pressures to Improve Service Delivery

1. Ability to Identify Clients and Use Sources of Funding

As for the third factor, it is apparent from three sources in the data that the agencies were not experiencing external pressures to improve or be accountable for their service delivery system. First, as shown in Table V above many of the agencies were unable to identify AADD clients by age or disability which suggests that there were few external pressures to keep accurate records--at least accurate records of AADD clients served. Accurate records in service organizations are kept in order to insure future funding or because of control agent sanctions if they are not kept. Second, as shown in Table XIII above, the relative scarcity of federally funded compared with state funded agencies providing services suggests that federal monies are perhaps not being well used. The study of Chicago area AADD services (Hamilton, Betts, *et al.*, 1977) found that funding sources were not being utilized to the fullest extent possible. There appeared to be little external pressure in the forms of encouragement or assistance for agencies to acquire or seek monies that are available. This situation needs to be investigated to see why agencies are ignoring the federal source of funds--if indeed they are.

2. Perceived Obstacles to Service Delivery

Perceptions concerning obstacles to delivery of services were surveyed by means of the following question: "What do you consider as major problems in providing services to older/aged developmentally disabled clients?" Results appear in Table XVI. A list of obstacles was included, as was a space beside "Other" in order to allow for the agencies to provide additional obstacles. Only one of the twenty agencies filled in the "Other" space. Its response was "Lack of staff and poor coordination and planning." Across all agencies, the most frequently noted obstacles were Inadequate Funding (75%), Transportation (55%), Lack of Supportive Community Services (50%), and Attitudes of the Community (50%). Interestingly enough, these responses describe quite accurately the sad condition of services for the AADD population as found in the literature. The obstacles perceived as having minimal importance were: Staff Development (35%), Development of Individual Plans (35%), Difficulty of Maintaining Staff (35%), Difficulty of Finding Staff (30%), Certification and/or Licensing (10%).

These responses are understandable for the following reason: if agencies are not providing services especially designed for the AADD population, then the less the agencies would be apt to be concerned about service implementation such as staff development or with the problems associated with staff expansion. But more important they provide indirect information about the existence of the external pressures on the agencies to provide services. This will be discussed in the next section.

Table XVI

Perceived Obstacles to Providing Services by Agencies Providing Services

OBSTACLES	PUBLIC #	PUBLIC %	NURSING #	NURSING %	CONSUMER #	CONSUMER %	TOTAL #	TOTAL %
Inadequate Fund.	6	66.6	7	77.7	2	100	15	75
Transport.	7	77.7	4	44.4	0	0	11	55
Lack of Comm. Support	4	44.4	6	66.6	0	0	10	50
Attitudes of Commun.	3	33.3	6	66.6	1	50	10	50
Client Attitudes	2	22.2	2	22.2	0	0	4	20
Diffic. of Finding Staff	1	11.1	5	55.5	0	0	6	30
Staff Training & Devel.	3	33.3	4	44.4	0	0	7	35
Diff. of Maintain. Staff	3	33.3	4	44.4	0	0	7	35
Develop.Indiv.Prog.Plans	3	33.3	4	44.4	0	0	7	35
Certif. &/or Licensing	0	0	2	22.2	0	0	2	10
Severity Client Handic.	2	22.2	4	44.4	0	0	6	30
Other	0	0	0	0	0	0	0	0

DISCUSSION

The survey data proved useful in providing answers to the three questions this particular study was asking. In addition to the discussion of the findings, brief mention will be made concerning what the state of Illinois is doing to improve services for this client. But before the discussion begins, it is worth noting that, considering the number of AADD persons estimated to be living in the two sampled areas, very few agencies are providing services to meet even their most basic needs. This was particularly true for those persons who were not yet 65 years of age. Perhaps this accounts, in part, for why the bulk of the services being provided by those agencies sampled were of the survival or maintenance kind, rather than of the kind which will help the individual achieve some level of independent functioning in the community. But then again, as will be discussed later, the treatment and change technology which should help the younger AADD client achieve the latter, needs to be developed.

Returning to the intention of the study, which was to answer three questions about human service organizations and their behavior, much support was found to substantiate the ideas that the organizations surveyed are indeed behaving as expected given the existence of the internal and external factors which affect their behavior.

A. Lack of Definition of the Population

First of all, the agencies' responses did reflect the general lack of knowledge concerning all aspects of this needy population. The inability of many agencies (40%) to identify the number of clients being served by age and by disability suggests that even those agencies that provide services either do not have sufficient knowledge of who this client is or do not have this client defined as a specific target for service--and hence feel there is no need to keep records. This also means that AADD clients are being served, as Thomas and Acker (1978) suggested was the case, by programs which are not specifically designed for the AADD client, such as social security, welfare, public health, and the like, for whom AADD clients happen to fall under their umbrella of services.

The inability of agencies to identify unmet needs as well as the small percentage of clients in their community area being served (less than 45%) underscored their lack of knowledge about the AADD client. The person is then it certainly seems reasonable that they cannot know how many exist in their community.

B. State of Development of the Treatment Technology

With respect to the second factor, the kinds and frequency of services provided was consistent with what is presently known about treatment and change technology. The bulk of the services being provided met only the survival or maintenance needs of the AADD client. Educational, occupational training, sheltered employment, and other services which would enhance independent living were the least provided services. In addition, none of the agencies reported innovative services which they were attempting to develop or provide.

A contrasting finding which requires some discussion was the following: a substantial number of agencies (65%) responded that, given additional funds and staff, they would develop and add services beyond what they were already providing, especially such additional services as educational and vocational training and sheltered employment. This is a positive note which if taken at face value indicates that the agencies surveyed do not find it outside of their realm of concern to help this population with needs that are fairly evident. If money were indeed available to them, would they live up to their public promises? This is a question which needs to be answered because of implications for future planning. Perhaps what some agencies need is expertise on how to obtain monies to provide those additional services.

C. External Pressures to Improve Service Delivery

Using the perceived obstacles responses as evidence for the lack of external pressure from the community and the client, is an exploratory effort, meaning that the evidence must be indirectly inferred. The following discussion, therefore, must be viewed with caution and with an eye for its heuristic value in later, more rigorous research efforts.

Closer inspection of agencies, other than by nursing homes, which reported that "Community Attitudes Toward Clients" was an obstacle, revealed those agencies who were providing the most intense and personal services to the client, such as sheltered employment, educational programs, food services, and transportation, to name a few. (Nursing homes were not included because they would be expected to be concerned about the community's attitudes towards themselves and their clients, given the nature of their status in the community.) The agencies which did not respond to this question generally were those agencies which provided the least personal services such as welfare agencies, social security, or public medical services. These latter agencies, it could be argued, did not perceive community attitudes as an obstacle because their services are more impersonal, and because they were less concerned about why clients were not coming in for services or did not want to take advantage of services, than were agencies providing personal services. Nevertheless, what is being said here in an indirect manner, by responses as well as non-responses, is that community attitudes toward AADD persons are negative and unlikely to pressure agencies to provide services to this client. Similarly, those agencies (20%) who considered client attitudes as an obstacle, as well as those who did not respond, were saying indirectly that if client attitudes keep them from even making the effort to receive services, then these clients are not likely to fight for their right to adequate services.

Finally, an interesting finding was obtained by further analyzing the obstacle question. Some of the responses to the obstacle question, if taken collectively, could be called "implementation variables" (e.g. "Difficulty of finding staff," "Staff training and development," "Development of Individual Program Plans"). These provide some additional information about the services the agencies provided to the AADD client. Human service organizations, if they have special programs or are in the process of implementing special programs, usually are concerned about implementation, especially when there is a paucity of knowledge about these special programs and, as a consequence, of trained personnel to provide the service. Conversely, if special programs were nonexistent, then agencies would not be concerned with implementation variables. Analysing the data, we find that the consumer agencies did not perceive these three as obstacles, the public agencies perceived them somewhat as obstacles, while the nursing homes perceived them considerably more as obstacles (this increase could be attributed, perhaps, to the nature of their services and their economic sources and structures, as well as their questionable status in the community). To some extent, this reasoning was substantiated when the public agencies who perceived these three obstacles were found to be, once again, those agencies that were the most involved in providing services for this client. For example, two agencies were specially mandated to serve both the elderly and the handicapped, and a third was an institute for developmental disabilities.

Thus we see some indirect evidence of an association with kinds of services provided by agencies and their perceptions of obstacles and we find some consistency between organizational behavior and perceptions: that is behavior influences perceptions. The obstacle question, or any form of it then, has some value for the kind of information, such as perceptions, that it can provide about the organization. It is effective because it does not appear to be intrusive and hence the organizations surveyed would not perceive it as a threat to their operations. For these reasons the use of such an indirect technique for obtaining information has heuristic implications for future research. That is, this technique could be better structured and integrated into a questionnaire with the intent of relating the information obtained to the behaviors the organizations have reported.

EFFORTS BY THE STATE OF ILLINOIS TO SERVE AADD CLIENTS

The state of Illinois, according to their State Planning Council's list of objectives and activities (Region V: State Planning Council Profile, 1978), is making a major thrust to provide and develop employment programs, special autistic and cerebral palsy program units, deinstitutionalization projects, and training programs at all levels. In addition, and perhaps, more important, the Council plans to target in on the lack of utilization of federal funds available through various legislative programs. These objectives and plans appear to be consonant with the needs to improve the knowledge base and to expand the present service situation which is due in part to the lack of knowledge about the AADD person and the lack of utilization of federal funding.

Illinois is also interested in developing service technologies, as these are related to the plans to improve services mentioned above. However, it is uncertain whether the state is interested in developing innovative programs of the type mentioned by Segal (1976): that is those types which will meet their sexual expression, spiritual needs, and the like. As indeterminant needs these are difficult for organizations to implement, but it is important that they be developed and provided, for not only does this person have a right to these services but these kinds of services counter the prevailing societal attitudes that view AADD persons as less than human.

With regard to enhancing community understanding and support, the Council has established the following goal: "Provide greater emphasis on community acceptance of DD persons by undertaking a state-wide program, and one program at a local community, to increase community acceptance of DD persons" (Region V: State Planning Council Profile, 1978). As for the AADD person's input into planning programs, the State Planning Council has eleven members who have developmental disabilities or are parents or guardians of a disabled child. No plans, however, have been made to help them become involved on the local level. The Illinois State Developmental Disabilities Council is not making provisions for the creation of external forces or "control agents." Furthermore, while other states in Region V have at least made plans to influence governmental executives and legislators to be supportive of legislative programs for the AADD client, Illinois has not.

SUMMARY

First, analysis of the data using the conceptual framework outlined in the investigative questions which were derived from the research on human service organizations provided information about three factors (lack of definition of the target population, state of the treatment technology, and external pressures) which shape the delivery of services to the AADD client. Second, the survey data provided some useful information about the condition of services for the AADD client in the state of Illinois.

It was found that the lack of knowledge that exists about the AADD client was reflected in the service behaviors of the agencies surveyed. A large percentage of agencies were unable to identify their clients by either age or disability. In addition, agencies were unable to identify unmet needs and the number of clients not receiving services in their community. Services were found to be generally of the survival and maintenance types, rather than those which would enhance the independent functioning of the AADD client. Also, a considerable number of agencies responded that if additional funds and staff were available, they would provide additional services. Whether they actually would or could add new services was questioned because of the problems inherent in organizational implementation.

It was found too that positive external pressures from the community, the client, and "control agents," which would help shape the service delivery system of the organizations, essentially do not exist. And finally, the "obstacles" question in the survey was discussed as a useful technique for obtaining, in an unobtrusive manner, additional information about organizational behavior.

In addition, the plans and goals that the state of Illinois has established to improve the services for the AADD client were discussed. These plans and goals were found to be, to some extent, consonant with the issues presented in the study.

In conclusion, this study stresses that the factors that shape the human service organizations' behavior must be understood and considered as important in the emerging efforts to rationally improve the service needs of the AADD client. For if organizations are indeed adaptive organisms, the adaptive behaviors they develop might not benefit the client as intended, but rather benefit the organizations themselves, serving merely as self-survival behaviors (Scott, 1974).

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INDIANA

Jay Levinthal

METHODOLOGY

The sample population for the survey consisted of those agencies which might be expected to offer services to the AADD population. Within each state in Region V (Indiana in this case) one major urban area (Indianapolis) and one university community (Fort Wayne) were selected. These two areas were selected on the assumption that a high number of AADD persons could be found in urban areas, and that human services tend to be concentrated in university communities. This specific community selection itself raises an issue with regards to the AADD population; they are many times "invisible" (Dickerson, 1974). Identification of AADD persons is extremely difficult in urban areas and even more so in rural areas.

Phone directories for these areas were used in selecting the service agencies (public, private, consumer, nursing homes, public schools, colleges, and universities) to be sampled. Except for nursing homes all the agencies were included in the sample. After a random start, every fifth nursing home was selected and included.

Once the sample was selected, the revised questionnaire, along with accompanying materials including a self-addressed return envelope, was sent to 64 agencies in Indiana. A period of six weeks was used as a cut-off date for questionnaire return. Of the 64 agencies surveyed in Indiana, 38 returned the questionnaire for a response rate of 59%. Babbie (1973) has indicated that any response rate to a mailed questionnaire which exceeds 50% is sufficient for analysis and limited inference. Thus the response to the AADD questionnaire was sufficient to draw general conclusions and make inferences concerning service to AADD persons within the state of Indiana.

The method of sampling selection (use of phone directories and the choice of population areas), and the nominal nature of the variables limit permissible analysis. However, that does not detract from the significance of the relationships found. Although the statistics are primarily descriptive in nature, statistical analysis was performed and inferences can be made. Babbie (1973) states that when two variables are nominal, lamda is an appropriate measure. Lamda is based on the reseacher's ability to "guess" each respondent's value on one of the variables.

Besides lamda, simple correlations, analysis of variance, and chi-square were used to analyze the data. Only those correlations which were significant at the .05 level and above with a lamda value of .50 and above were used.

Despite these statistical limitations, the survey has educational and practical significance. It describes the current state of affairs in Indiana for AADD persons.

FINDINGS

Agencies Sampled

Of the 64 Indiana agencies receiving questionnaires, 38 (59%) of the agencies responded within the given six-week cut-off period. Twenty-three (61%) of the 38 responding agencies reported that they were serving the AADD population.

Of the 23 agencies serving the AADD population, 10 (44%) were public agencies, 5 (22%) were nursing homes, 4 (17%) were consumer oriented, and

2 (9%) were private agencies. A complete summary of the data appears in Table I.

Table I

The Agencies Sampled

	NUMBER RESPONDING	NUMBER SERVING POP.	% SERVING	% OF TOTAL (23) GROUP SERVING
Public	15	10	67%	44%
Nursing	7	5	71%	22%
Private	4	2	50%	9%
Consumer	4	4	100%	17%
Public School	2	0	0%	0%
College	5	1	20%	4%
Unknown	1	1	100%	4%
TOTAL	38	23	61%*	100%

*: $\frac{23}{38}$ x 100

The small number of respondents within certain agency types (colleges, consumer groups, public schools, private agencies) limits our ability to make generalizations about such agency types. However, certain trends and statements of fact can be made regarding the services provided and/or the obstacles to service which appeared to exist within the agency types.

People Served

1. Age Range & Agency Type. Within the specified age ranges a total of 944 AADD persons were identified by 9 (39%) of the 23 serving agencies. This total was about evenly distributed with 265 persons (28%)

in the 35-54 range, 307 persons (32%) in the 55-64 range, and 372 persons (40%) in the 65+ age group. See Table II.

Table II

Age Range Served and Agency Type
(N = 944)

AGE	AGENCY											
	3 PUBLIC		3 NURSING		1 PRIVATE		1 CONSUMER		1 UNKNOWN		9 TOTAL	
	#	%N	#	%N	#	%N	#	%N	#	%N	#	%N
35-54	250	26.5	7	0.7	0	0	7	.7	1	0.1	265	28.1
55-64	300	31.8	3	0.3	0	0	2	.2	2	0.2	307	32.5
65+	300	31.8	27	2.9	10	1.1	0	0	35	3.7	372	39.4
TOTAL	850	90.1	37	3.9	10	1.1	9	.9	38	4	944	100

If we use fifty-five years of age as a reference point for separating the aging DD person from the aged DD person, we find that 28.1% of our identified DD persons in Indiana are under 55, and 71.9% are over 55. Although 71.9% seems high, it reflects to a degree a recent finding that DD persons are usually unaccounted for between the ages of 35 and 55, yet reappear sometime after age 55 (Hanff & Keiter, 1977).

Ninety percent (90%) of Indiana's age identified population came from public agency sources, yet this represented only three of the ten public agencies surveyed who said they served AADD persons. Consumer agencies were not serving anyone over the age of 65.

2. Developmental Disability & Agency. Nine of the serving agencies (39%) supplied information as to the developmental disabilities of their clients. The breakdown by developmental disability is as follows:

	NUMBER	PERCENTAGE
Multiple Handicap	325	44%
Mental Retardation	293	40%
Autism	75	10%
Epilepsy	29	4%
Cerebral Palsy	13	2%
TOTAL	735	100%

Of the 735 DD persons identified, 706 persons (96%) were reported by six agencies, two public agencies (78%) and four nursing homes (18%). In each disability category except epilepsy, public agencies identified the majority of persons. A complete summary can be found in Table III.

Table III

Number of Clients Served by Agency and Developmental Disability
(N = 735)

	AGENCIES RESPONDING	EPILEPSY	C.P.	AUTISM	M.R.	MULTI	TOTAL #	TOTAL %N
Public	2	11	10	50	202	300	573	78
Nursing	4	12	2	25	73	21	133	18
Private	1	2	0	0	6	2	10	1.5
Consumer	1	0	0	0	9	0	9	1
College/Pub.Sch.	0	0	0	0	0	0	0	0
Unknown	1	4	1	0	3	2	10	1.5
TOTAL	9	29	13	75	293	325	735	100
%N		4	2	10	40	44		

Public agencies identified 573 clients by disability, the largest share (78%) of those identified. However, the figure came from only two agencies. Four nursing homes identified 133 clients, 18% of those identified, and seemed to be providing service to a wide range of disability types.

3. Number of AADD Persons Served. Due to the nature of the questionnaire and the propensity of agencies to overestimate the number of clients served, it was impossible to determine the actual number of AADD persons served. These attempts were further confounded by the possibility of a client being served and reported by more than one agency.

However, with this in mind, the approximate number of AADD persons reported served by the responding service-delivery agencies were as follows:

	NUMBER
- Identified as both DD and as age 35 or over	944
- Identified as both DD and as residing in an additional nursing home (hence, probably age 35+)	96
- Additional public agency	400
approx.	1440

4. Ability to identify AADD clients. Only 39% of the agencies supplied client information by age or developmental disability. Of the twelve agencies (52%) who acknowledged that their "records are not kept in those categories" only six (26%) responded that the categories were inappropriate.

After almost five years there still appears to be a "need to identify the DD population regarding the age and type of developmental disability among its constituents" (Dickerson, 1974).

Public agencies, although serving the greatest number of AADD persons, are lax in keeping age and disability records about the people they serve. On the average only 25% of the public agencies were able to provide this type of information. The performance by the other agencies, although better, was still far short of the effort needed.

Services

Services available ought to be a reflection of what is needed by an individual throughout his/her life. At present most services provided to AADD persons are similar to those offered to young DD persons, and for the DD individual between the ages of 18 and 55 very little is offered which would specifically deal with the needs of that individual.

1. Services Provided and Client Needs. To help facilitiate the analysis of trends and priorities within the service-delivery population, the following grouping of services was used:

1. LIFE SKILL SERVICES
    a. educational
    b. vocational
    c. sheltered workshop
2. PSYCHOLOGICAL SERVICES
    a. diagnostic
    b. counseling
    c. in-home site visits
3. HEALTH SERVICES
    a. medical care
    b. dental care
4. LEGAL, PROTECTIVE, AND SUPPORTIVE SERVICES
    a. legal
    b. guardianship
    c. personal advocacy
    d. income maintenance
5. LIVING ARRANGEMENT SERVICES
    a. foster care
    b. other residential care

6. ANCILLARY SERVICES

a. transportation
b. information
c. activity and recreation
d. staff development

Each of these services (which by and large are mandated by P.L. 94-103) meets one of the needs of the AADD person. Ideally, what is needed are services which are appropriate to and for the individual and which also benefit the individual's community or society at large.

Before looking at the services provided by the different agency types it is helpful to examine the services provided by the group as a whole. A categorical breakdown of the types of services provided follows:

Service Group	Percentage of Agencies Providing
Ancillary services	63%
Psychological services	52%
Health services	33%
Life skill services	30%
Legal and protective services	19%
Living arrangement services	19%

There can be little doubt about the importance and need for a wide range of services for the AADD person. However, emphasis, priority, and appropriateness of the services is perhaps the more important issue. Gordon, in his Temple University Study (1977), found the unmet needs of the AADD person to be:

1. medical and dental care;
2. psychological diagnosis and counseling;
3. residential placement and day care;
4. educational and vocational training;
5. financial assistance; and

6. recreation and transportation.

Most respondents for the agencies (84% were administrators) thought they were offering the right type of services to their clients. When asked "what other services would you provide to meet the needs of the AADD client?", the two top responses were "transportation services," and "none." Other responses were: diagnostic services, income maintenance services, educational equipment, and more of the same, each named only once.

The services most frequently cited by the 21 agencies were information (81%); adult activity/recreation (61%); diagnostic and transportation (each with 57%); staff development (52%), and counseling service (48%). The services provided least often were: foster care (5%); guardianship (10%); personal advocacy (14%); legal services and sheltered employment (each at 19%); dental (24%); and vocational services (29%).

2. Services Provided and Type of Service. Overall, ancillary services rank first in services provided (53%) followed by psychological services (52%), health services (33%), protective and supportive services (19%), life skill experiences (30%), and living arrangement services (19%). (See Table IV.)

Of the services provided, the ones most frequently used are listed in Table V.

Analysis of variance revealed that for public agencies there was no statistical significance for any of the services provided. There was only a high probability that information services would be offered.

Table IV

Categorical Services Provided by Agencies

	OVERALL	PUBLIC	NURSING HOMES	CONSUMER AGENCY
Life Skills	30%	15%	0%	100%
Psychological	52%	39%	60%	100%
Health	33%	37%	53%	0%
Legal & Protective	19%	19%	30%	14%
Living Arrangement Ser.	19%	6%	30%	50%
Ancillary Services	63%	47%	75%	88%

Table V

Frequency with which Agency Services are Used by Agency

PUBLIC	NURSING	PRIVATE	CONSUMER	COLLEGE
1. Info.	1. Medical	1. Educ.	1. Shelt.Emp.	1. Educ.
2. Income	2. Activity	2. Transp.	2. Transp.	
2. In-home	3. Oth.Res.	3. Income	3. Activity	
3. Stf.Dev.	3. Stf.Dev.	4. Activity	4. Educ.	
3. Counsel.	4. Dental	5. Info.	5. Info.	
3. Transp.				

All five of the nursing homes serving the AADD population provided medical services, adult activity/recreation services, and staff development services, and four of the five provided diagnostic services. None of the nursing homes provided educational, vocational, or sheltered employment services.

The breakdown by type of services provided was as follows:

	PERCENTAGE
Ancillary services	75%
Psychological services	60%
Health services	53%
Legal services	30%
Living arrangement services	30%
Life skill services	0%

The most frequently used services by the AADD person in nursing homes were medical and dental services, recreation services, other residential services and staff development services. It is interesting that nursing homes provide few other-residential services, yet it is one of the most frequently used. With studies showing that many persons are inappropriately placed in nursing homes (Hitzing et al., 1978; Dickerson, 1974), it is fairly clear that increased allocation of resources for other-residential services are needed.

With 73% of the persons living in these nursing homes over 65 years old, it is not surprising that no life skill services are offered. However, there is a need for "more programming," as one nursing home identified this unmet client need, and studies are showing that individuals have learning potential throughout their entire lives.

The most frequently offered and used ancillary service for AADD persons in nursing homes was recreation. This finding is substantiated in a study of 100 Indiana nursing homes by Austin and Peccarelli (1977). One hundred percent of the responding nursing homes offered some sort of recreation service. The recreation activities provided were letter writing, entertainment, parties, games, arts and crafts, community events, painting etc., all "leisure time activities."

"Leisure time activities" are integral parts of many programs serving the AADD person. This finding was supported by Dickerson (1974) in her study of MR adults placed in institutions. However, innovation in recreation programs is needed. Austin and Peccarelli noted that "an increase in utilization of the elderly person's intellectual capacities is a large area for potential program expansion" (1977, p. 6.).

Austin and Peccorelli also found that staffing problems are quite prevalent in nursing homes in regards to recreation directors. Thirty-two percent of the recreation directors had worked less than one year. It was also reported that staff development resources were also the most frequently offered and used by nursing homes in our current study.

Analysis of variance tests revealed that nursing homes were more likely to offer recreation services, medical services, diagnostic services and staff development services than other agency types.

They were also highly unlikely to offer educational, vocational, sheltered workshop services, legal, advocacy services and foster care services.

All the consumer groups for retarded persons surveyed in our study provided educational, vocational, sheltered workshop services, diagnostic and counseling services.

Breakdown by service categories was as follows:

	PERCENTAGE
Life skill services	100%
Psychological services	100%
Ancillary services	88%
Living arrangement services	50%
Legal services	14%
Health services	0%

Consumer agencies seemed to be primarily involved with providing AADD persons alternative living arrangements, employment, educational opportunities, and psychological services. They appear to provide broader, more varied types of services to the AADD person. However, they seldom provide legal/advocacy services, and health services.

The five most frequently *used* services, in descending order, are sheltered employment, transportation, adult activity, educational, and information services. Least frequently used services include vocational services, counseling, health services, and the protective and legal services.

Analysis of variance showed that consumer groups were statistically more likely to offer educationl services, vocational services, and recreation services. There was also a high probability that they would offer diagnostic services, information services, and other-residential services.

As in the other agency types they are also *not* likely to offer any legal, protective, and supportive services to the AADD person.

In regard to the service delivery agencies, findings indicate that in regards to types of services provided the most frequently provided services are either ancillary services (transportation, information, and recreation) or psychological services (diagnostic and counseling). These two service categories were either ranked first or second by all of the agency types.

In regards to life skill services, health services, living arrangement services, and legal services, differences did appear by agency types. Generally speaking, for nursing homes and public agencies the least provided services were in the life skill areas, the legal and protective area, or the other-living arrangement category. For these agencies little if any emphasis was placed on educational, employment services, advocacy and legal services, and other residential services.

Consumer agencies, although they provided education and employment services, did not stress personal advocacy, other-residential alternatives, and health services.

Currently, federal and state regulatory and planning agencies emphasize the importance of education, employment opportunities, legal rights, and community-based living arrangements for the AADD person, yet these types of service were not often provided by the serving agencies.

Funding Source & Services

Twenty (20) service delivery systems provided funding source information. Of these 20 agencies, 16 were receiving federal funds, 11 received state funds, 7 received county funds, and 6 received private funds. Only 6 of the agencies received funds from a single source, while the remaining 14 agencies received funds from a combination of sources. Table VI provides a detailed breakdown of services provided by agencies receiving various kinds of funding.

1. Federally Funded Agencies. Sixteen agencies (84%) received some degree of federal funds. These agencies most frequently provided ancillary services (59%), followed by psychological services (56%), health (33%), life skills (29%), protective (23%), and living arrangements (22%) (See Table VII).

Two ancillary services, information (81%) and adult activities (63%), ranked one and two as far as the services most provided by federal agencies. Diagnostic services (63%) tied for second and counseling and transportation tied for fourth with 50%.

Less than 25% of the federally funded agencies provide sheltered employment services, guardianship services, dental services, personal advocacy services and foster care (These services involve personal rights, productivity, and alternative living arrangements, all major goals in federal legislation).

Table VI

Services Provided by Funding Source

N = 19

SERVICE	N = 16 FEDERAL		N = 11 STATE		N = 7 COUNTY		N = 6 PRIVATE	
	#	%	#	%	#	%	#	%
I Life Skills								
Education	6	38	5	46	3	43	1	17
Vocational	5	31	3	27	3	43	0	
Sheltered Employment	3	19	3	27	3	43	0	
II Psychological								
Diagnostic	10	63	7	64	6	86	4	67
Counseling	8	50	8	73	5	71	1	17
III Health								
Medical	6	38	5	46	3	43	1	17
Dental	4	25	3	27	2	29	3	50
In-home	6	38	4	36	3	43	2	33
IV Protective & Supportive								
Legal	4	25	4	36	2	29	1	17
Guardianship	2	13	2	18	1	14	1	17
Personal Advocacy	2	13	2	18	2	29	2	33
Income Maintenance	7	44	3	27	2	29	3	50
V Living Arrangements								
Foster Care	1	6	1	9	1	14	1	17
Other Residential	6	38	6	55	4	57	1	17
VI Ancillary								
Transportation	8	50	6	55	4	57	4	67
Information	13	81	9	82	6	86	4	67
Activity/Recreation	10	63	7	64	5	71	5	83
Staff Development	7	44	5	46	3	43	5	83

Table VII

Funding Sources & Services

	OVERALL	FEDERAL	STATE	COUNTY	PRIVATE
Life Skills	28%	29%	33%	43%	6%
Psychological	62%	56%	68%	79%	42%
Health	39%	33%	33%	33%	56%
Protective	26%	23%	25%	25%	29%
Living Arrange.	27%	22%	31%	36%	17%
Ancillary	60%	59%	61%	64%	75%

In regards to frequency of use, the services used most often are information, recreation, transportation, medical services, income maintenance services, and sheltered employment services (See Table VIII). Differences existed between the types of services provided and the services used most often by the AADD person. The services used most often were those which coincided more directly with federal priorities.

Table VIII

Frequently Used Services by Funding Source

	FEDERAL	STATE	COUNTY	PRIVATE
	1. Info.	1. Activity	1. Shelt.Emp.	1. Activity
	2. Activity	2. Medical	2. Info.	2. Medical
	3. Transp.	3. Info.	3. Transp.	3. Educ.
	4. Medical	4. Transp.	3. Activity	4. Transp.
	5. Income	5. Shelt.Emp.	4. In-home	5. Other Res.
	6. Shelt.Emp.	6. Educ.	5. Educ.	

2. State Funded Agencies. Eleven (58%) of the service delivery agencies were receiving some percentage of state funds. Overall, state

funded agencies provided psychological services most frequently (68%), with ancillary services second at 61%. Life skills, health services, protective and supportive services, and living arrangement services were provided by 25% to 33% of the agencies.

Specifically, information, counseling, diagnostic, and adult activity services were offered most often. Other residential services, education, staff development, and transportation are offered more frequently (by percentage) by state funded agencies than by federally funded agencies.

As with federally funded agencies, the least offered services were the personal advocacy services, guardianship, and foster care services, with vocational and sheltered employment not far behind.

The most frequently used services were adult activities, medical, information, transportation, sheltered employment, and education. On the other end of the continuum, the least used services are vocational, personal advocacy, and foster care.

Analysis revealed that it was statistically significant that agencies receiving state funds were more likely to provide counseling services and other residential services. They also tended to provide adult activity services and information. There was also a high probability that they were not providing legal, guardianship, personal advocacy, and foster care services.

3. County Funded Agencies. Thirty-seven percent (37%) of the service delivery agencies responded to having some part of their revenue county based. Here again, as in state funding, psychological services ranked first. Ancillary services were next at 64%, followed by life skills (43%), living arrangement services (36%), health (33%), and protective services last (25%).

Information and diagnostic services were provided by 86% of the county funded agencies. Counseling and adult activities ranked second (71%), with other residential services and transportation next with 57% of the county funded agencies offering.

Generally speaking, the least offered services were protective and advocacy services and health services.

Frequently used services in county agencies were sheltered employment, information, transportation, adult activities, in-home service, and educational services. The least used are vocational, guardianship, personal advocacy, legal, and foster care.

4. Privately Funded Agencies. Six privately funded agencies provided ancillary services most often (75%); second were health services (56%), third psychological services (42%), followed by protective services (29%), living arrangement services (17%), and life skills (6%).

The most offered services were staff development, adult activity services, medical, information, diagnostic, and transportation services. This was highly consistent with the services offered by nursing homes, and with four out of the five nursing homes receiving private funds, this could be expected.

Least offered services were education, vocational, sheltered employment, other residential, and the protective and legal services.

Clients of privately funded agencies used adult activity services the most, with medical second, followed by education, transportation, and other residential services. Least used were vocational, sheltered employment, guardianship, personal advocacy, in-home treatment, legal, and foster care services.

Obstacles to Service

The final question of the survey was asked of all the agencies, whether or not they were delivering services to AADD clients. It asked what they thought the major obstacles were to their providing services to the AADD person. These agency-perceived obstacles represented the attitudes and perceptions of the agencies concerning both internal and/or external influences which ultimately presented obstacles to service for the AADD person.

1. Obstacles Perceived by Agencies Already Serving AADD Clients. Agencies already providing service to AADD clients mentioned inadequate funds (43%) as their major problem. If additional funds were available, the agencies said they would provide either more transportation or more of the same services but no new services. It seems agencies needed more coordination, supervision, and information from regulating and supervisory agencies in regard to program direction and priorities.

The next two most mentioned problems are both community oriented: 35% of the serving agencies felt that the attitude of the community toward its clients was a major obstacle, 30% cited the lack of community supportive services (30%).

The difficulty of maintaining program staff was seen as a problem by 30% of the serving agencies, all of which were either nursing homes or consumer agencies. Other major problems for the serving agencies were client attitude (26%), lack of transportation (26%), and severity of clients' handicap (22%).

For the serving agencies, staff training and development, certification/licensing, and IEP's were not seen as major obstacles. The serving agencies were certified already, and eleven out of the twenty-three serving agencies were providing staff development for their staff.

Nevertheless, increased knowledge about AADD persons and their needs, and the advent of alternative services to AADD persons, will require improved training for staff personnel. (Hammer & Richman, 1975).

Service over and above custodial care for AADD persons, will require new directions in service and will demand active participation from both staff and clients (Coons, 1973).

2. Obstacles Perceived by Agencies Not Serving AADD Clients. Agencies not serving the AADD person, also cited inadequate funds (40%) as the most frequent obstacle. Interestingly, lack of transportation services was perceived by as many agencies (40%) as a major obstacle to providing service, whereas only 26% of agencies already serving AADD persons saw this as an obstacle. Transportation was one of the most frequently provided and used services for the AADD person. With more community-based homes for the AADD person, plus more community involvement by the AADD person, increased need for transportation services can be predicted.

Staffing also was cited as a major barrier to service for non-serving agencies. Of the fifteen non-serving agencies, five (33%) reported difficulty of finding qualified staff. Staff training and development (27%) and difficulty of maintaining the staff (27%) were also important obstacles. These findings are summarized in Table IX.

Twenty percent of the non-serving agencies perceived lack of community supportive services, certification/licensing problems, and the development of individualized program plans as obstacles to providing services.

Table IX

Obstacles and Service

OBSTACLE	N = 38 TOTAL #	%	N = 23 SERVING #	%	N = 15 NON-SERV. #	%
No Trans.	12	32	6	26	6	40
IEP	7	18	4	17	3	20
No Staff	9	24	4	17	5	33
Staff Developmennt	5	13	1	4	4	27
Maintenance of Staff	11	29	7	30	4	27
Community Attitudes	9	24	8	35	1	7
No Supporting Services	10	26	7	30	3	20
Severity of Handicap	7	18	5	22	2	13
Client Attitudes	7	18	6	26	1	7
No Money	16	42	10	43	6	40
Certification	4	11	1	4	3	20

Generally speaking, for non-serving agencies community attitude toward the AADD person, client attitude, and severity of clients' handicap were not seen as barriers to service.

With more and better-trained staff, transportation, and funds, non-servicing agencies felt they could be providing service to the AADD person. AADD persons themselves were not seen as a barrier to their receiving service.

3. Obstacles to Service Perceived by Public Agencies. The major obstacles for service delivery cited by public agencies were inadequate funds, lack of transportation, poor community attitude and support, and poor client attitude with one out of three agencies remarking that it has these problems. Client attitude and developing individualized program plans, 20%, were the next most cited obstacles.

Problems with staffing were almost non-existent, with only one agency remarking that it had problems in staff training and development. Note that staff development services was one of the services most frequently used by public agencies.

For public agencies serving AADD clients, the obstacles were generally perceived as client or community oriented, and possibly represented a disagreement between program priority and community/client priorities. More research certainly needs to be done in this area.

For public agencies not serving AADD clients, lack of transportation was perceived as a major obstacle to providing service (cited by 2 out of the 5 non-serving public agencies).

4. Obstacles to Service Perceived by Nursing Homes. Seven nursing homes responded to the survey; five of them were serving AADD persons. The two non-serving nursing homes did not identify any obstacles or problems to providing services to the AADD person.

Four of the five serving nursing homes identified the major obstacles as difficulty in finding qualified staff and difficulty in maintaining staff, even though all five nursing homes provided staff development services to their staff. (Nursing homes were the only serving agency which identified difficulty in finding qualified staff as a barrier.) The difficulty nursing homes had with staffing could be related to the low salaries, minimal benefits, and possibly the lack of stimulating and interesting work in the nursing homes.

Other major barriers for nursing homes were lack of supporting community services, community attitude toward clients, severity of clients' handicap, and inadequate funds.

Nursing homes were generally isolated from the surrounding community. They were usually self-contained, care-oriented programs where broad-based community involvement was minimal. (Transportation, for instance, was not seen as a barrier to providing services, and was also one of the least used services.) The relationship between community and nursing home presents itself as a problem for the nursing home.

5. Obstacles to Service Perceived by Consumer Groups. The major barriers to service perceived by consumer agencies (all of which provided services to the AADD population) were client attitude, community attitude, and difficulty of maintaining staff (75% of the consumer agencies). Lack of community supportive services and inadequate funds were the only other barriers to service identified, each at 50%.

Consumer groups appeared to have a higher degree of contact with community services, and they attempted to find sheltered employment, alternative living arrangements, and educational classes for their AADD clients. They seemed to perceive a need for improved attitude and cooperation both from the community and from the AADD person.

6. Obstacles to Service Perceived by Private Agencies. Of the agencies serving AADD persons, only lack of funds and transportation were seen as obstacles to service. Non-serving private agencies, in addition to these two problems, included difficulty of maintaining staff and certification/licensing as major obstacles.

Although only a small number of responding agencies were privately operated, they seemed to have problems in acquiring certification and in maintaining quality staff.

There was no mention of community or client-oriented barriers to providing services. The role that private agencies played, in the state of Indiana, in providing services to the AADD person was sketchy.

7. Obstacles to Service Perceived by Colleges and Universities. One college serving AADD persons identified the following barriers to

providing services: inadequate funds, transportation, severity of clients' handicap, and the difficulty of developing individualized programs.

Besides the lack of funds and transportation, the major barriers seemed to be knowledge related. Knowing more about AADD persons and their needs might help in developing individualized programs to compensate for the severity of the client's handicap, and hence to provide access to educational facilities.

Of the four non-serving colleges, lack of funds and difficulty of developing individualized programs were cited as the biggest barriers to providing services to the AADD person. Lack of transportation, the perceived problem of the severity of the AADD person's handicap, plus recruiting, training, and maintaning staff were most mentioned. The general impression was one of limited involvement for colleges and universities.

8. Obstacles to Service Perceived by Public Schools. Two non-serving public schools identified lack of funds and difficulty in finding qualified staff as the major obstacles to providing service. Transportation, lack of community supportive services, difficulty of training and maintaining staff were other obstacles.

Both colleges and public schools needed funds from state agencies to provide services. Without state aid, direction, and initiative, education (including self-care education, vocational and/or sheltered employment services) will seldom be provided to the AADD person in Indiana.

IMPLICATIONS

It has been said that the aging/aged developmentally disabled person faces a rather unique and devastating situation because of the "double jeopardy" which permeates their existence. The "double jeopardy" of being both aged and disabled, and the special problems which accompany these conditions. However, recent studies have confirmed what common sense has told us all along.

Being aged and disabled are not the only "jeopardies" which confront the AADD person. A third "jeopardy" confronts the AADD poplulation for, in most instances, they also happen to be poor (Hamilton & Betts, 1977). Without employment opportunities, they are generally dependent on federal and state monies or family support and these sources on the average provide only a minimal degree of sustenance. This picture ultimately results in almost total negation of any positive feelings of self-worth and makes them victims of a system which allegedly exists for their support (Ryan, 1971).

Current legislation is intended to alleviate the effect of these conditions and to improve the overall quality of life for the AADD person. Federal legislation stipulates: first, the DD person's right to treatment and habilitation in the least restrictive environment in order to maximize a person's potential; second, the achieving or maintaining of economic self-support to prevent, reduce or eliminate dependency; third, the achieving or maintaining of self-sufficiency, including reduction or prevention of dependency; fourth, the preventing or remedying of neglect, abuse or exploitation; and fifth, the preventing or reducing of inappropriate institutional care by providing for community-based care, home-based care, or other forms of less intensive care.

These goals by and large coincide with the perceived needs of the AADD person. Needs as delineated by Kriger (1975), Dickerson (1974), and Gordon (1977) fall into the following categories:

1. health and nutrition needs;
2. financial needs;
3. alternative living arrangement needs;
4. legal and protective needs;
5. employment opportunities; and
6. educational needs.

Priorities and goals have been established or delineated by the Indiana State Plan for Developmental Disabilities (1978), and although they are not specifically geared to the AADD population they certainly will affect the quality of life of the AADD person.

First priority is residential services, the goal being that Indiana will assure that a continuum of residential services is available for all DD persons.

Second priority is community programs, the goal being a continuum of community-based services which will develop in comprehensiveness and quality.

Third priority is prevention, the goal being reduction of the incidence and prevalence of DD.

Fourth priority area is comprehensive services, with a goal of extending the scope of educational, health, rehabilitation, habilitation, planning, and related services to provide comprehensive, quality services to DD persons. Adequate training of professionals and paraprofessionals is a sub-goal.

Fifth priority is planning, with a goal of ensuring that adequate services for the DD person are appropriate to changing needs in a cost effective, coordinated manner.

Sixth priority is protection and advocacy services, with a goal of ensuring that the environment in which habilitation and rehabilitation of every DD person takes place provides for optimal balance between program and civil and personal rights. (Indiana State Plan, 1978)

These priorities cover a period of five years: yet for the present the two major service needs specified by the plan are in special education and in community and residential services. Accompanying services in need of improvement are diagnostic and evaluative services; management and counseling services; physical, occupational, and speech therapy; and transportation (Indiana State Plan, 1978).

The overall goal of both federal and state legislation is to maximize the potential of the AADD person. The objectives of the regulatory and supervisory governmental agencies are different, yet they ultimately influence the degree of independence of the AADD person, the self-sufficiency of the individual, and the right of the AADD individual to fulfill his/her potential.

Services are needed which improve and provide for the welfare, health, self-sufficiency, self-worth, productivity, and rights of the AADD individual. Currently, gaps in services are quite apparent with agencies generally providing information services, adult recreation, transportation services most often. Services involving legal and protective issues, education, vocation, health and the nutrition of the AADD person are greatly lacking.

Although agency types differ in regard to the types of services they provide, the effort of all agencies should be directed toward meeting the advocacy, living arrangement, financial, pyschological, educational and employment needs of the AADD person. Over and above the providing of these services resides the issue of constructive and meaningful communication among the agencies, community and clients (or their caretakers).

In conjunction with providing the types of services delineated by the federal and state priorities, it is imperative that Indiana also begin to keep more and better records of the clients they serve. In order to provide the appropriate services to the AADD population, it is important to know the clients type of developmental disability, their age, and how many of these persons are being served. Further, increased federal intervention and support can only be actualized with this information.

The present study indicates the existence of gaps in the services provided to the AADD person and supports the selection of the above priorities. With the advent of the zonal system in Indiana, it is hoped that many of the problems inherent in the old system will be overcome (problems primarily with coordination and communication between and among agencies, communities and clients). For Indiana, comprehensive services and the coordination of these services should be the two main objectives in providing services to the AADD person.

Beyond the issues of comprehensive and coordinated activities and services lies the question of quality, appropriateness, and innovation. Unlike the services which are presently provided to the AADD person, which are generally static and sustaining in nature, new services must now become more dynamic and risk oriented. For the aged DD person, the die is already cast. Younger DD adults and aging DD persons are the ones who will directly and ultimately reap the benefits of innovative programs and comprehensive services in Indiana. Providing for basic health needs is fundamental for all AADD persons, but promoting dignity, self-worth, self-sufficiency, employment, educational opportunities, and personal advocacy could very well actualize the potential of human beings who by and large have three strikes against them.

SUMMARY

This survey, despite its methodological limitations, makes clear a number of important observations and conclusions regarding the current state of affairs regarding the AADD person in Indiana.

1. Thirty-eight (38) of 64 agencies surveyed responded to the questionnaire, and 23 (61%) of the agencies reported that they provided services to the AADD population.
2. Excluding than public agencies, which served all ages of AADD persons with the same frequency, all other agency types provided services to a particular age group of AADD persons. Nursing homes primarily served the 65 years and older age group: 73% of the AADD population in nursing homes was over 65. Private agencies also served only AADD individuals 65 years or older, but consumer agencies served only AADD persons younger than 65 years old.
3. Ninety percent (90%) of the age identified population came from public agencies, yet this represented only three of the ten service-providing public agencies. The other seven agencies did not report the age of their clients.
4. Ninety six percent (96%) of those individuals identified by developmental disability, were reportedly being served either by public agencies (78%) or by nursing homes (18%).
5. Only 39% of the agencies serving AADD persons provided age related information, and similarly, only 39% of the agencies provided developmental disability information.
6. Approximately 1440 AADD persons were receiving services from 11 (48%)

of the 23 serving agencies. Twelve (52%) of the agencies, although they reported that they were providing services for AADD persons did not provide information as to the age or type of disability of their clients.

7. Ancillary services (transportation, recreation, information, and staff development) were the most frequent services provided by agencies (63%) who were serving AADD persons.
8. Psychological services were provided by 52% of the agencies while health services and life skill services were offered by approximately 30% of the agencies.
9. Legal and protective services as well as alternative living arrangement services were on the average offered the least, with only about 20% of the agencies providing these services.
10. Public agencies showed no clear cut emphasis or priority by the services they provided, after information services (89%) there was no other service which was offered more than 50% of the time.
11. Nursing homes emphasized certain types of services while demphasizing others. Ancillary services, psychological services, and health services were offered by more than 50% of the nursing homes, while legal and protective services and alternative living arrangement services were offered by only 30% of the nursing homes.
12. Other than legal and protective services, and health services, consumer agencies provided broader, more varied types of services to the AADD person than other types of agencies. However, these agencies served no one over the age of 65.
13. Universities, colleges, and private agencies were not serving any significant number of AADD persons.

14. Three service delivery agencies (two public agencies and one nursing home) identified 410 AADD persons who reportedly were not being provided services.

15. Nursing homes and consumer agencies had major problems in maintaining qualified staff.

16. Inadequate funds, lack of transportation, and staffing were the major obstacles to service perceived by nonserving agencies.

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ASSESSMENT OF COMMUNITY SERVICES FOR THE OLDER/AGED DEVELOPMENTALLY DISABLED POPULATION: A REPORT ON SERVICES IN MICHIGAN

Douglas Ensor

Introduction

The purpose of this paper is to summarize the results of the study of services to the aging and aged developmentally disabled (AADD) residents of Michigan, done by the Institute for the Study of Mental Retardation and Related Disabilities. This survey was done under the auspices of the Developmental Disabilities Office, U.S. Dept. of H.E.W. in 1977 and 1978.

The methodology and research tasks of this study have been addressed earlier in this volume by Dwight Sweeney. This report will address itself to the four central issues of the survey as reflected in the Michigan state responses.

These questions are:

a) How many AADD persons are receiving services from the agencies surveyed?

b) Identification of already existing services available to this population;

c) Determination of additional services needed by AADD persons; and

d) Identification of obstacles to effective service delivery.

A number of difficult questions arise in analyzing the results of a survey dealing with the AADD population. These difficulties of definition, jurisdiction, and interpretation reduce the degree of precision of the results and increase the epistemological dilemmas unique to this relatively new field of formal study.

Findings

In Michigan, eighty-six agencies provided information for this study. Of those responding, 57% said that they were indeed providing services for the AADD population. Most questionnaires were completed by program administrators (86%).

The majority of agencies were public ones (43%) followed by nursing homes (19.8%), consumer-oriented agencies (11.6%), universities and colleges (11.6%), private agencies (8.1%), and finally public schools (5.8%).

Agencies reported serving DD clients from one year of age to 110 years of age, with a total census of 1543 clients older than age thirty-five during the 1977 calendar year. See Table I.

TABLE I

Age category	35-54	55-64	65+	TOTAL
Number of clients	646	301	596	1543
Percentage	41.9	19.5	38.6	100%

These clients were reported to have the following primary diagnoses:

TABLE II

Mental Retardation	1526
Multiply Handicapped	304
Epilepsy	85
Cerebral Palsy	68
Autism	0

Since these diagnoses total more than the number of clients, it is apparent that these categories overlap, and were viewed that way by the responders.

A number of agencies were not able to respond to these questions as to number and type of AADD client served. The most frequent reason was that records are not maintained by such categories (30%) and that these categories are not applicable to this sort of agency (13%). This difficulty has been addressed by Dickerson et al. (1974), and will be discussed later in this article.

What services are typically provided by these agencies? Questions are asked about a wide range of services, and there were responses in all of those categories. Table III reports the percentage of responding agencies that provide various services.

TABLE III

Information/referral	38.4%
Adult activity/recreation	31.4
Transportation	25.6
Staff development/inservice	19.8
Educational classes	19.8
Medical treatment	16.3
Diagnostic assessments	14.0
Personal advocacy	14.0
In-home services	12.8
On-going counseling/treatment	12.8
Dental treatment	9.3
Other residential care services	8.1
Income maintainance	7.0
Vocational classes	7.0
Sheltered employment	5.8
Foster care	5.8
Legal services	4.7
Guardianship	2.3

Three additional services were provided by the agencies: day care, service coordination and home repair.

When agencies were asked to rank order the five most frequently rendered services, information/referral, adult activities, and medical treatment were most frequently reported. The frequency of the medical treatment and adult activities categories was especially prominent for nursing homes.

Agencies appeared to be relatively satisfied with their array of services, as most who responded when asked what other services they would provide if additional funds and/or staff were available responded, "More of the same." Nevertheless, 29% said that there are unfilled client needs to be met, and that the agencies needed to be more active in identifying AADD clients. Only 18.6% of the agencies had identified "unserved" AADD clients.

Agencies reported their sources of funds as follows:

TABLE IV

Federal	38.4%
State	29.1%
Private	25.6%
County	18.6%
Special Grant	10.5%

Obviously, some programs receive funding from multiple sources.

All agencies (those who currently provide AADD services and those who do not) were asked to identify the major problems in serving the needs of the group of AADD people. The lack of adequate funds was mentioned by 61.6%, but the list of responses is instructive as to the complexity and interlocking nature of these difficulties.

TABLE V

Major Problem	Percentage Reporting
Inadequate funds	61.6
Transportation	48.8
Lack of community supportive services	41.9
Difficulty of finding trained staff	26.7
Staff training and development	24.4
Severity of client's handicap precludes use of service	23.3
Developing individualized program plans	22.1
Attitude of community toward clients	20.9
Difficulty of maintaining staff	19.8
Do not usually serve *	16.3
Client attitude	11.6
Certification and/or licensing	8.1

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*This response was volunteered to the "other" category.

There are many obstacles reported at a significant level by these agencies. The "do not usually serve" response is interesting for it seems to reflect a number of different conditions.

Sometimes it reflects a lack of training in identification and assessment of DD persons. At other agencies it reflects the fact that records do not always follow clients who have made the mysterious transition from "retarded" to "old" (Dickerson, 1974). This issue will also be discussed at a later point in this paper.

The responses to this questionnaire in Michigan comprise 26.5% of the total (six state) Region V sample.

Discussion

There are a number of important concerns which have been addressed by the other authors in this volume as to the limitations on analyses of this data. I share these fully, but will not repeat them here. I would suggest that the most fruitful approach to quantitative analysis of the data would be pursued on the Region V level, rather than on the state levels. Nevertheless, a number of qualitative issues are raised by these findings.

As the AADD clients age, they are not exempt from the feelings, prejudices and fears we hold about older people in general. B.W. Richards (1975) states in his article on Mental Retardation and Aging:

> "Death is the most serious and inevitable consequence of aging (for all people), but is usually preceded by a period of time, which may be years, during which declining intelligence, impairment of memory, and other sources of mental impoverishment or of physical deterioration reduce employability and social competence." (p. 368)

Richards goes on to note, from his English data, that the DD individual is more likely to be subject to institutionalization with age than are other people.

We might add that they are more likely to be targets for agency intervention as their existing supports for adequate coping, such as family, friends, or guardians, also age. As these informal support persons become stressed through illness, separation, financial reverses or other problems, these AADD individuals are likely to "reappear" with needs expressing a dependency of minor or major sort.

Dickerson et al. (1974) raise an interesting question that also addresses the issue. They suggest that "old" appears at an earlier age for the DD individual. They propose that the DD person is in double or triple jeopardy with the sensory, physical and support network losses of increasing age.

I would also say that some of the so-called "community" placements for MR middle-aged persons may provide as complete a socialization into a new role "impairment" as did the "total limitations" that Goffman (1961) has so eloquently described. In Michigan, for example, a group of former residents of MR institutions are housed in nursing homes. These clients are substantially lower in age than the usual clients of the homes and are often in satisfactory health. Few people would seriously argue that they are in appropriate "least restrictive environments" for their abilities, and in fact they are often described as good candidates for more nearly mainstream community placements. But, in the peculiar logic of such things, they are low priority to be moved. They are, you see, already placed. They are also, perhaps, "aging" with unnatural speed if we think of aging not only as a biophysical process, but also as a socialization process.

The status of AADD clients in supervised community care in Michigan has been questioned, most recently by the Michigan Association for Retarded Citizens (1979).

An estimated 19,000 individuals require Adult Foster Care in Michigan. The Adult Foster Care Licensing Division, is responsible for monitoring 3037 licensed homes. They have received 686 complaints in a recent 10 month period, 59% of these related to allegations of resident abuse, neglect and/or exploitation (MARC, 1979). Recent budget cutting plans would leave the division with about 50% of the staff required to monitor these homes (34 instead of 66 positions).

As was suggested earlier, the difficulty that some agencies found in responding to questions about diagnostic categorization of their clients is important and implies a number of things simultaneously. The diagnostic vocabulary for the DD population is clearly not shared consistently by many of the agencies that are serving older DD clients.

Sometimes this may be simply because the DD label bears no relevancy to the agency's charge, with no detrimental results for the client. At other times, the diagnostic information may not have followed the client at an age-transition point (e.g., from public school to community employment), and the DD client may now essentially resemble the traditional client of the agency. If his situation requires modifications of the typical service program delivery, he may or may not receive appropriate service.

This latter situation implies a number of important questions about the status of the field. Is it possible that for whatever reason the AADD client is served appropriately by agencies which don't "know" the developmental/diagnostic information deemed important in this survey? While we cannot say this is so (and it is legitimate to doubt it), neither can we state unequivocably that the "invisible client" would be better off if identified.

This question is at the edge of two relatively new fields - the study of aging and the study of the later life stages of developmentally disabled clients. In the clear absence of "categorical services" for the AADD client, the "masquerading" client - one who "seems like" a member of a served population - may be in the best position to be served at this point in time.

If categorical services are to develop for AADD clients, as they have for these people at other ages, a good deal of education of service agency staff will be required. We have to share a vocabulary. We will have to look closely at how some needs of AADD individuals are different from - and presumably some the same as - non-DD clients.

We will need to rethink our ideas of "development." Despite Erik Erikson's work of so many years now, we still focus almost exclusively on the developmental needs of 0-18 year olds (or at best 0-26 year olds since P.L. 94-142 and Section 504 of the Rehabilitation Act of 1973 as amended.) A book like Gail Sheehy's Passages becomes a best seller because of a society's surprise; life-span development is still a novel notion.

There is another problem here, though. Richards (1975) suggests that for both aging and AADD individuals, we are close to identifying a population of "surplus" individuals. We have created a society where older people are non-essential in various ways: in the workforce, in our homes, in our schools.

Braginsky and Braginsky (1971) have properly described the evil we engender with those children that are our contemporary "Hansels and Gretels" - children who end up in residential settings for social reasons and reasons of depleted resources rather for their psychological or medical problems.

In a society where forced retirement is the norm, it is unlikely, for example, that vocational training for older DD clients could find wide support, regardless of the value for the individual.

The DD client may not be joining a new group as he or she ages. It may be all of us who are doing the joining. The experience of being extra, of being surplus, of being unnecessary will be new for only some of us.

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DATA FROM

ANALYSIS OF MINNESOTA

Rochelle Flumenbaum

INTRODUCTION

Since the Dickerson, *et al*. paper, there has been an increase in public attention to the AADD adult. State and federal planners have established statewide, regional, and national data banks about the prevalence and needs of the developmentally disabled of all ages and about the services available to them (e.g., Minnesota Governor's Planning Council, 1978; Region V UAP Consortium Project, 1979; Yuker et al., 1977). However, these data banks still do not directly refer to the needs and characteristics of AADD adults as a specific group with perhaps special needs. Likewise, legislation such as the Rehabilitation Act of 1973, the Older Americans Act of 1965 Titles IV and VII, the Developmental Disabilities Services and Facilities Construction Act of 1972, the Developmentally Disabled Assistance and Bill of Rights Act of 1975, and the Special Health Revenue Sharing Act of 1975, while not directly allocating funds for the AADD population, have in part been reanalyzed from the point of view of the AADD adult (e.g., EMC Institute, 1977).

More direct attention has been given to the AADD population by various needs assessment studies (e.g., Hamilton, *et al*., 1977; Temple University Rehabilitation and Training Center, 1977; Kriger, 1975) and by the few national conferences which have been held on the joint area of developmental disabilities and gerontology (e.g., Hamilton & Segal, 1975; Segal, 1978). Further, The Institute for the Study of Mental Retardation and Related Disabilities (ISMRRD), along with 4 other University

Affiliated Facilities (UAF) have been federally funded to expand interdisciplinary training, services, and research activities regarding the AADD population (Oregon, Georgia, Nebraska, Utah).

ISMRRD contracted to spend one year surveying the 6 states of Region V as well as other UAFs in order to provide a data base for future planning and decision-making about the AADD population. The particular objective of this chapter is to analyze this data for the state of Minnesota.

The meeting of this objective and the breadth and quality of the data base for Minnesota are naturally limited by the form in which data was collected and by the questions asked. Various agencies were surveyed to: 1) determine the number and type of AADD persons they served; 2) identify existing services available to this group; 3) determine additional services this group requires; and 4) identify obstacles to effective service delivery. Thus, this research effort is agency-focused and the data base established necessarily becomes an assessment of community services for the AADD population. Only indirectly does the survey create a data base about the prevalence, needs and characteristics of the AADD population.

However, this survey is useful to the extent to which it sheds light on whether or not the "cloak of invisibility" (Dickerson et al., 1974) has been removed from the AADD population and to what degree community agencies and placements perceive, acknowledge, and respond to the AADD population. Further, the survey is useful to the extent that it details the kinds of services offered to the AADD population. This is a particularly important area.

First, although a relatively small percentage of the DD population has resided in institutions (Scheerenberger, 1977), many of the DD population who were and are being deinstitutionalized are aging or aged developmentally disabled. They were born in an era when limited options were available to the families of the developmentally disabled (Gollay, et al., 1978). Deinstitutionalization requires a myriad of services for the previously institutionalized and their families, as well as preparation of the community at large into which the previously institutionalized are placed (Gollay, et al., 1978; Stedman, 1977a; Scheerenberger, 1977; Dokeckie, et al., 1977). The service needs resulting from deinstitutionalization and the transition to community life have been listed by professionals dealing with deinstitutionalization (Stedman, 1977a); by the developmentally disabled and their families (Gollay, et al., 1978; Yuker, 1977); and indirectly by life-cycle psychologists who emphasize personality continuity theories of aging for the general population (Sieg, 1977).

Second, those aging and aged developmentally disabled who were at no time institutionalized but who lived with their parents have most likely outlived their primary caretakers (Segal, [illegible] Kriger, 1975). This transition involving loss, change of caretaker, and probably change of lifestyle demands a particular set of services for the AADD person (Segal, 1978; Kriger, 1975). Whether deinstitutionalized or deprived of their primary caretaker, AADD personss require services to prepare them for a change in lifestyle, and to prepare the community for receiving these persons.

Last, available community services may have to be assessed from the point of view of all aged/aging DD, of this generation and of the future, given that studies of the interaction between aging and developmental disabilities could present the AADD population as a special group because of special biological, psychological, and social characteristics. For example, while the direction of biological changes may be the same for both the elderly and the aging developmentally disabled, baselines may be different or rates of change may be different (Callison, et al., 1971; Lawton, 1966).

METHODOLOGY

Questionnaire

The original project workers, Nola Thomas and Jane Brock, designed a questionnaire with the intent of surveying community agencies known to be serving the AADD population. Based upon information obtained from 23 Washtenaw County, Michigan, agencies participating in their pilot study, these workers revised their questionnaire. Also, because so many of the agencies responding to the pilot survey used different definitions for identifying their AADD clients, each revised questionnaire included cover sheets operationally defining "developmental disabilities" and the four disability types. Agencies also received a description of the purpose and objectives of the ISMRRD project along with questionnaires.

Sampling

The sample for the survey was selected to be representative of community agencies throughout HEW Region V. For Minnesota, as for the other states of Region V, the sampling technique involved selecting a major urban area and one university center. Minneapolis/St. Paul and Duluth were the urban and university areas selected, and Hennepin, Ramsey, and St. Louis, their corresponding counties, were selected as the sample areas. The Twin Cities also represented a university center as well as an urban center.

An urban area was selected because large numbers of elderly persons are typically concentrated in urban areas according to census data. Further, service agencies also tend to be concentrated in urban areas while university centers also tend to have a concentration of service programs. These assumptions are confirmed by the 1978 Minnesota DD State Plan's estimates of the number of aging/aged DD clients residing in Hennepin, Ramsey, and St. Louis counties as compared to other counties and by the Plan's breakdown of the number of human service agencies for the developmentally disabled throughout Minnesota (Minnesota Governor's Planning Council on DD, 1978, Sections II, III).

It was felt that if service gaps appeared in urban/university areas, then these gaps would most likely also exist in the more rural areas. However, this sampling technique fails to survey service providers in the more rural areas of Minnesota. Given the rural character of much of Minnesota, valuable information is unavailable regarding services which might be particularly relevant to the needs of AADD clients living in rural areas. Further, generalizations are limited to the extent that characteristics of a population in heavily populated areas might not parallel population characteristics in rural areas and that persons with DD tend to move to areas with concentrations of services so that urban prevalence estimates do not necessarily reflect rural prevalence estimates.

Next, a list of Federal, state, county, and local agencies which consisted of public, private, and consumer agencies, nursing homes, public schools, colleges and universities was compiled. This list was compiled from local telephone directory listings of facilities found under 37 Key Word headings. These Key Words appear below.

Key Words Used in Survey

Mental Retardation
Epilepsy
Nursing Homes
Retirement
Goodwill
Salvation Army
Consumer
Public Schools
Colleges/Universities
Social Services
Social Security
Welfare
Education
Adult
Special Education
Recreation
Human Services
Protection
Advocacy
Cerebral Palsy
Autism
Lawyer Referral
Association for Retarded Citizens
Planned Parenthood
United Way
Community Services
Group Homes
Half-Way Houses
Aging
Senior
Independent Living
Vocational Rehabilitation
Mental Health
Nutrition
Developmental Disabilities
Homemakers
Legal Assistance

Unfortunately, the Key Word listing by which agencies were selected omitted some crucial key words. "Intermediate care facilities--MR"; "developmental achievement centers"; "residential facilities"; "community residential facilities"; and "supervised living facilities" were omitted from this listing. These omissions probably occurred because of the nature of telephone directory classification, because of overlapping terminology, because of oversights on the part of the survey constructors, and because many of these settings primarily serve young DD clients. These Key Word omissions lessen the effectiveness of the sample generated from the Key Word listing and in turn, limit the generalizability of the survey data because many facilities specifically mandated to serve the developmentally disabled client in the community were not included in the sample.

Further, these Key Word omissions make it difficult to determine which agencies included in the sample are specifically licensed or certified to serve the DD client. While the State Plan specifies the number of nursing homes, boarding care homes, group homes, and ICF-MR facilities licensed or certified throughout Minnesota, it does not supply a comprehensive listing of the names of the facilities in each of these categories, but rather in just some of these categories; nor does it specify overlaps such as nursing homes which are ICF-MRs. However, in cross-checking all available listings, it appears that just one, or perhaps two, of the surveyed nursing homes are specifically licensed or certified to serve DD clients. Thus, for example, generalizations regarding nursing homes not specifically licensed to serve DD clients are still plausible and are useful since these nursing homes are technically inappropriate community placements for these clients.

These Key Word omissions also contribute to fairly small sample size which further limits the validity and generalizability of the survey data. While 20% of the nursing homes accurately represents 20% of the actual number of nursing homes in Hennepin, Ramsey and St. Louis counties, the 100% of agencies surveyed corresponding to Key Words does not represent 100% of the agencies in some way serving the DD client. For example, as of 1977, there were 26 Developmental Achievement Centers licensed under Deprtment of Public Welfare (DPW) Rule 31, 71 Community Residential Facilities for Persons Having Retardation under DPW Rule 34, and 3 Community Residential Facilities for Persons Having Physical Handicaps licensed under (DPW) Rule 80 in Hennepin, Ramsey and St. Louis counties (State Plan, Section III). None of these facilities were included in the survey sample, which may or may not pose a problem given that many of these facilities serve a young DD clientele only and that some of the people living in these facilities were represented in the data supplied by large agencies such as the Department of Vocational Rehabilitation. The entire survey sample is constituted by a total number of 77 agencies responding from the three-county area specified. Because there are no definitive records of the number of agencies serving a developmentally disabled clientele it is unclear what proportion of the applicable agencies in these counties were in fact represented by the 77 sampled agencies. Hence, compilation of sampling error is unfeasible for this study.

Lastly, the sample may be poorly distributed regarding representation by agency type. Except for nursing homes, agency types were not systematically sampled according to the proportions in which they may exist in the community or in the various counties because it had been assumed that 100% of all agencies were being sampled. As a result, the sample includes more public agencies (33% of all respondents) and nursing homes (40% of all respondents) than any other kinds of agencies.

C. Response Rate

Once the sample was selected, the questionnaires and cover sheets were mailed to the 77 Minnesota agencies, along with stamped, self-addressed return envelopes. After approximately 4-6 weeks, a follow-up packet was mailed to those agencies which did not respond to the original mailing. Of the 77 questionnaires, 6 were returned because facilities were no longer in operation or because of incorrect addresses. Of the remaining 71 questionnaires, 45 were returned, completed by the deadline date. This constitutes a 63% response rate which exceeds the 50% response rate necessary for the analysis of mailed questionnaire survey data (Babbie, 1973). It was also the best response rate among all six states in Region V (see chapter by Dwight Sweeney).

Data Analysis

The nominal nature of the questionnaire data, the small sample size, the inability to estimate a sampling error for the survey, poor distribution of agency type sampling, and the essential sampling omissions pose constraints on the statistical analysis and interpretation of results. Nonetheless, the data does lend itself to simple descriptive statistics. Thus, the body of the analysis is comprised of percentages and frequency distributions.

The dichotomous nominal variables were also treated as interval scales so that data analysis was not limited to simple descriptive statistics. Where suggested by the descriptive analysis of data, simple correlations, analyses of variance, and chi squares were computed. Only those tests significant at or above the .05 level with at least 50% of the variance accounted for are reported here. Strengths of association were estimated by use of the Goodman-Kruskal Lambda technique; those associations with predictive power exceeding a lambda value of .50 were felt to be significant for the chi square computations.

RESULTS

Agency Ability to Provide Demographic Information

Of the 45 agencies surveyed, 28 (62%) reported that they served AADD clients. Ability to specify the total number of AADD clients served helps to evaluate the 62% figure more closely. Of these 28 serving agencies, seven (25%) could not specify the total number of clients served and two made "wild" estimates. How did these agencies know they were serving AADD clients if they could not specify how many?

Among the 62% of agencies claiming to serve AADD clients, 32% could not provide information by clients' age and 43% could not provide information by clients' disability type. Table 1 describes the number and percentages of serving agencies able to provide information on the total number, age, and disability type of their AADD clients.

Table 1*+

SERVING AGENCIES (N)	# PROVIDING INFO. ON TOTAL # CLIENT (%)	# PROVIDING INFO. BY AGE (%)	# PROVID. INFO. BY DISABILITY (%)
Public (9)	5 (56)	3 (33)	2 (22)
Private (2)	1 (50)	1 (50)	0 (0)
Consumer (2)	2 (100)	2 (100)	1 (50)
Nursing (13)	13 (100)	13 (100)	13 (100)
Pub. Sch. (1)	0 (0)	0 (0)	0 (0)
Col./Univ. (1)	0 (0)	0 (0)	0 (0)
TOTAL (28)	21 (71)	19 (68)	16 (57)

*: small sample size and possible skewed sampling distribution necessitate caution in interpretation

+: all figures rounded to nearest whole number

The inability to provide information by total number of AADD clients, by age category, and by disability type emerged as a pattern with public school and colleges/universities unable to provide any demographic information; nursing homes able to provide all information; and public, private, and consumer agencies inconsistently providing some information.

It is understandable that public schools lacked the necessary information since they do not typically serve the AADD client, but public agencies are mandated by federal law to maintain records at least by disability type. Interestingly, 14 or 50% of the 28 serving agencies checked off our records question indicating they were unable to specify either age, disability, or total number of AADD clients information. Of these 14 agencies, 10 (36%) said that records were not maintained by age or disability categories and 3 (11%) said that these categories were not applicable to their agency. Of the 10 agencies which did not maintain records by age and/or disability categories, 7 agencies were public agencies, all of which are mandated by law to maintain these records.

Number of AADD Clients Served

Those agencies able to furnish information about the total number of AADD clients served accounted for 1098 persons ages 35 plus. Two other agencies, branch offices of one county's Social Security Administration, provided estimates of the total number of persons served by their offices without regard to age and/or disability. Using the 4.3% prevalence rate for DD suggested by EMC, 80 AADD persons (representing the largest estimate of the number of AADD persons possibly served by these Social Security branch offices) were added to the 1098 person count resulting in a total of 1178 AADD persons ages 35+ served by the agencies surveyed. This number is probably an overestimate because there was duplication in counts among public agencies and non-public agencies whose clients very likely used more than one of the agencies surveyed.

The Minnesota State Plan 1978 (II.6 - II.10) estimates that the total population of the three surveyed counties--Hennepin, Ramsey, and St. Louis--for the year 1980 will be 1,686,200. The U.S. statistical abstracts (1976) estimates that 41.5% of the population or 699,773 people are 35 years old or older. Using EMC's 4.3% prevalence rate for developmental disabilities, we estimate that 30,900 persons in Hennepin, Ramsey, and St. Louis counties will have a developmental disability, with 2.08% of the population or 14,555 persons having a severe disability for the year 1980. While there are some differences in developmental disabilities prevalence rates (President's Commission on Mental Retardation, 1977; Tarjan, 1973), Minnesota's state planners use a 2.422% prevalence rate, 1.893% of which represents those who are substantially mentally retarded which in turn, represents almost 74% of all disabilities. Thus, their projected figures for 1980 closely reflect EMC's 2.08% prevalence rate for severe disabilities (State Plan II.11 - II.34), with 16,949 people projected as having a developmental disability for the year 1980.

To project the total number of AADD persons being served in the sampled areas of Hennepin, St. Louis, and Ramsey counties, a few assumptions have to be made. We must assume that all agencies who reported serving AADD persons were providing services at the same rate as those surveyed; that the percentage of non-responding agencies providing services was the same as agencies responding to our survey (although this assumption may lead to an overestimate since non-serving agencies might have a greater tendency not to respond to the questionnaire); that 20% of all nursing homes in the 3-county area are represented by the survey; and that at least 40% of non-nursing home agencies are represented by the sample. For this last assumption, the survey staff hoped to sample 100% of all non-nursing home agencies. However, 100% of all other agencies could not possibly have been sampled (see Methodology Section of this chapter) and 40% represents a far more realistic, though perhaps low, estimate of the number of public, private, consumer, public school, college/universities sampled over the three counties.

Given all these assumptions, the maximum total number of AADD persons receiving services in the sample areas is projected to be 8888. Hence only 30% of the expected AADD population were being served or 61% of the expected AADD population with severe disabilities (assuming that all AADD persons receiving services were severely disabled, an unlikely assumption). Thus, with the most generous assumptions about the data, at least 40% and 70% of the projected AADD population in the 3-county area were not receiving services. This in areas where services were assumed to be concentrated. However, Minnesota's agencies, in comparison with the agencies of the other states of Region V, served a larger percentage of AADD clients. Exact proportions are available in the other papers of this monograph.

1) Number Served By Age Group. Analyzing the data on the number of clients served in particular age categories uncovered a large discrepancy between the number of clients served in the 35-54 year group and the number of clients served in either the 55-64 or 65+ age groups (Table 2). Although the data showed a general downward trend which might reflect increasing mortality rates of DD clients with age, it is unlikely that so many clients could fall out of the service picture because of death. Nor is it likely that the unequal age intervals account for the extreme decrease in client numbers in the 55+ age group compared to the 35-54+ age groups.

Table 2

Age Category	# of Clients	% of Total Sample (1178)
35-54	820	70%
55-64	162	14%
65+	111	9%

While it is a positive sign that 70% of the AADD clients represented by service agencies in our sample were being served during the prime years of their life, we have to wonder what becomes of these clients when they become 55 years old. (Editor's note: Minnesota is the only state reporting this result. Other states reported more clients served in the 55-64 and 65+ age range.) Over 600 people seemed to disappear from agency counts once they became 55 years old. Did these 35-54 year olds drop out of the service system when they reached 55 years, not to reappear until they applied for Social Security or were placed in nursing homes or institutions? Because Social Security had no records by age or disability type, they could not estimate the number of AADD clients served by age category. Interestingly, two of the Social Security branch offices said that they served AADD clients from ages birth to 65 with no particular age breakdowns; these branches did not cite one DD person who was over age 65 although the largest percentage of all Social Security clients were above age 65. Some of these 65+ year olds must have been developmentally disabled. It is difficult to account for the large decline in numbers of people receiving services in the older age groups.

To some extent, the decline may have been an artifact of a skewed sample because the Department of Vocational Rehabilitation accounted for 729 persons in the 35-54 age group, 117 people in the 55-64 age group, and 11 people in the 65+ age group. If data from Vocational Rehabilitation were omitted the number of clients would be more evenly distributed (Table 3).

Table 3

Age Category	# of Clients*	% of Subsample (N=236)
35-54	91	38%
55-64	45	19%
65+	100	42%

*: without Vocational Rehabilitation

By omitting Vocational Rehabilitation figures, we see that the decline in numbers of persons in the 55-64 age group could largely be explained by the unequal age intervals, and more importantly, that increasing mortality rates did not play a major role in determining the number of AADD persons in each of the age categories. In fact, the greatest number of AADD clients now appears in the 65+ age category. This figure most likely represented a group of people, not previously served by any agency, who appeared in the service system for nursing home placement or institutionalization. At the same time, omitting Vocational Rehabilitation information does not help us understand what becomes of those clients once served, who fall out of the service system at age 55.

Keeping the same assumptions as in projecting the potential total number of AADD clients served in the 3-county area in relation to prevalence estimates and using the Minnesota 1975 census information about the population in each of the age groups, we estimate that 23% - 48% of AADD persons in the three-county area in the 35-54 age range were served, 11-23% in the 55-64 year age range, and 8-17% in the 65+ age range. (Table 4).

If such relatively small percentages of the AADD population in all age groups were being served in these urban-university counties, probably even smaller percentages of AADD clients in all age groups were being served in other counties.

Table 4+

	- - - - AGE CATEGORIES - - - -		
	35-54	55-64	65+
1975 population for 3 counties	363,704	152,704	170,280
DD population for 3 counties*	15,639	6,540	7,322
Severe DD population in 3 counties**	7,565	3,164	3,542
Potential # of AADD persons served	3,618	720	595
% DD population served	23%	11%	8%
% severe DD population served	48%	23%	17%

*: Projected by EMC: 4.3% rate

**: Projected by EMC: 2.08% rate

+: all figures rounded to nearest whole numbers

2) Number of AADD Persons Served By Disability Type. Of the 28 agencies serving AADD clients, 16 (57%) were able to specify the primary diagnosis of each of their clients (see Table 1 above). Of the total 1178 clients reported served, 1015 primary diagnoses were provided. This represents 86% of the population served. However, nursing homes tended to duplicate their figures in the multiple handicap category because all surveyed nursing homes accounted for a total of 88 AADD clients but provided 102 primary diagnoses.

In contrast, of the 28 agencies serving AADD clients, 19 (68%) were able to provide information about clients by age category. This represented 1093 or 93% of the total AADD population served for whom age information could be provided.

Although age may have been a slightly clearer criterion for getting services, certain kinds of disability types were a more important factor in determining who was served. In a previous section we estimated how many clients in three age ranges were being served in the three- county area. Using Minnesota's 1975 census information for these three counties and using Minnesota's own prevalence estimates for mental retardation, cerebral palsy, epilepsy, and autism (Minnesota State Plan, 1978), we can estimate that for the age range 35+, 15% of the expected mentally retarded clients, 42% of the expected cerebral palsied clients, 100% of the expected epileptics, and 0% of the expected autistic clients were being served. No prevalence estimates were supplied in the State Plan for clients with multiple handicaps, so this category was omitted from the analysis.

This analysis by disability type suggests that epilepsy and, to a much lesser extent, cerebral palsy were important service determinants. Mental retardation and autism, however, were not important service determinants. This finding regarding retardation is even more important when one considers that Minnesota's 1.89% prevalence estimate for retardation reflects persons who are substantially retarded and does not include the mildly retarded. It is possible that AADD persons with even severe retardation, autism or to a lesser degree, cerebral palsy, tended not to be identified according to their disability and hence were not necessarily serviced according to their disability.

Services Provided

The four most available services to AADD clients were:

1) MEDICAL TREATMENT: 16 (36%) of the 45 responding agencies offered medical treatment. Of the 28 agencies serving DD clients, 57% offered medical treatment.

2) INFORMATION & REFERRAL: 15 (33%) of the 45 responding agencies offered information and referral services. Of the

28 agencies serving DD clients, 54% offered information and referral.

3) ADULT ACTIVITIES & RECREATION: 14 (31%) of the responding agencies offered adult activities/recreation. Agencies offering this service constituted 50% of the 28 agencies serving DD clients.

4) STAFF DEVELOPMENT/TRAINING: 12 (27%) of the 45 responding agencies provided staff training/development services. Agencies offering this service constituted 43% of the 28 serving agencies.

The least offered services were foster care, guardianship, legal services, and in-home services. Table 5 provides a comprehensive listing of the number and percentages of responding and serving agencies offering each service.

Table 5*

SERVICE	# OF AGENCIES PROVIDING	% OF SERVING AGENCIES PROVIDING (N = 28)	% OF ALL RESPONDENTS PROVIDING (N = 45)
Medical	16	57	36
Info. & referral	15	54	33
Adult activities/recreation	14	50	31
Staff develop./training	12	43	27
Counseling/treatment	9	32	20
Personal advocacy	9	32	20
Dental	8	29	18
Transportation	6	21	13
Diagnosis	6	21	13
Educational classes	6	21	13
Vocational training	6	21	13
Sheltered employment	5	18	11
Income maintenance	5	18	11
Other residential care	4	14	9
In-home services	2	7	4
Guardianship	1	4	2
Legal	1	4	2
Foster care	0	0	0
Other: nursing	2	7	4

*: all figures rounded to nearest whole number

No significant relationships with .50 strength of association were found between agency type and service apart from a relationship of .01 significance between adult activities and nursing homes. One interesting relationship significant at the .00 level was apparent between agencies which were able to specify the number of epileptics and those which offered life skill services. Life skill services are a collapsed group of direct services which include educational classes, vocational training, sheltered employment, and recreational activities. This finding augments an earlier estimate that all AADD persons with epilepsy were served by agencies in the three-county area. In turn, this relationship between agencies serving epileptics and their offering life skill services further suggests that epileptics are a "favored group," receiving services which are among the services most desired by AADD clients (see Gollay 1978 for clients' own perception of their service needs in the community).

Other tendencies noted relate to funding source and services offered by agencies. Federally funded agencies tended to offer indirect services such as information and referral and diagnosis while state funded agencies tended to offer direct life skills services. Both relationships were significant at the .01 level, the former having a .30 strength of association, the latter having .50 predictive power.

Services which Agencies Perceived are Necessary

Agencies were asked the "pot of gold" question concerning which other services they would provide to AADD clients if additional staff and funds were available. Of the 17 respondents, all of whom provided service, 3 or 18% would provide no other services; another 3 or 18% would provide day activities; 2 or 12% would provide transportation; 2 or 12% would provide work activities; and 2 or 12% would provide staff training. The other 5 agencies suggested: efficiency of service delivery, more of the same, information and referral, tutoring, and education classes.

Public agencies specified either no other services or more of the same. Other agency types also specified more of the same. Hence, nursing homes would provide more day activities, consumer agencies more outreach, and schools more staff training and referral.

Agencies were also asked if they had identified unmet client needs. A total of 25 agencies, 24 of which provided service, responded to this question, and 12 or 40% identified unmet needs of their clients. These included housing, transportation, work programs, day activities centers, more community involvement, staff training, diagnostic clarification, facilities services to rural clients, family subsidies, and more in-home services.

A small number of nursing homes identified clients' unmet needs, but this is consistent with an earlier finding that nursing homes tended to offer clients some degree of all of the possible services. Agencies of every type saw a need for work programs, but public agencies and consumer agencies also specified housing and transportation needs which nursing homes would logically not perceive as unmet needs of their resident clients.

DISCUSSION

The post World War II baby boom along with improvements in health care have resulted in increasing numbers of older developmentally disabled persons. This trend has been noted by a number of researchers in the field of developmental disabilities (Sayder & Wollner, 1974; Callison, et al., 1971; O'Connor, et al., 1970; Talkington & Chiovaro, 1969; Mueller &

Porter, 1969; Bell & Zubek, 1960). At the same time, shifts in the social conscience reflected in legislation emphasizing normalization, deinstitutionalization, the least restrictive environment, DD Councils and State Plans for the provision of service have brought attention to the developmentally disabled and, to a lesser extent, to the AADD. One of the goals of this research project is to assess the extent to which community agencies acknowledge and serve AADD persons in the community, or whether AADD persons are still under a "cloak of invisibility" as claimed by Dickerson, et al. (1974), and whether services provided are congruent with the needs of AADD persons.

Number of AADD Clients Served

Our survey results confirm that to a disappointing degree this population is very much cloaked by invisibility in Minnesota's Hennepin, Ramsey, and St. Louis counties' service systems, despite Minnesota's leadership in service provision for DD persons when compared to the other states of Region V. Some 38% of the surveyed agencies did not serve AADD clients. And many agencies who did serve AADD clients were unable to identify them by age, disability, or by total number of clients.

The most ominous sort of invisibility relates to members of the AADD population who are not being served at all. Using established prevalence rates to estimate the number of developmentally disabled persons, age 35 or older in Hennepin, Ramsey, and St. Louis counties for the year and generously estimating the number of AADD clients potentially served in 1978 by agencies in the three counties as measured by this project's own survey, we found that 40-70% of the expected AADD population were not being served by any existing agency.

By age groups, 52-77% of the expected 35-54 year old DD clients, 77-89% of the 55-64 year olds, and 83-92% of the 65 year olds and older were not being served by any agency in the three counties. However, these estimates demand caution because mortality rates for developmentally disabled persons are not known. These estimates use the mortality rates for the normal population.

By disability type, as defined in the Minnesota State Plan, none of the expected 35 year or older autistics, only 58% of the expected cerebral palsied 35 years or older, and 85% of the expected mentally retarded 35 years or older were not being served. On the other hand, it is estimated that all of the expected epileptics were being served.

Of all serving agencies, 32% were unable to identify their clients by age; 43% were unable to identify their clients by disability type; and 25% could not specify the total number of AADD clients they serve. Of these serving agencies, 36% did not maintain records by age and/or disability, despite federal legislation requiring that records be kept at least by disability type. Another 11% of the agencies said that age-disability categories were not applicable to their functions, whether or not this information was available from the records. Thus, for example, a Social Security branch only needed the general "disability" label in order to give payments. A nursing home only needed the general "disability" label in order to give medical and recreational services. As a result these services did not necessarily reflect clients' needs as determined by their specific disabilities.

Obviously, without age and disability information no data base with regard to the prevalence and service needs of AADD persons can be established. In turn, we question upon what basis do state planners develop their plans and upon what basis do agencies identify and report their service to AADD clients.

1) Ages Served. Age cannot be dismissed as a service determinant. While most DD persons in each of the age groups were not being served, more younger DD clients were being served than older DD clients. This finding can be analyzed from three different viewpoints.

First, the data could suggest that younger DD clients were most affected by the legislative shifts and normalization drives of the 1960s and 1970s. If the AADD persons in the 35-54 age group who are presently being served continue to receive service as they age, over the next 10-20 years this continuation of service will be measurable.

Second, younger DD clients may drop out of the service system as they age and not reappear in the service rosters until death of a caretaker results in institutionalization or nursing home placement. Increasing numbers of DD persons reside in nursing homes as one goes up the age scale compared to the decreasing numbers of DD persons served by other agencies. The fragmentation of services and agencies cited by Gordon (1978) would also contribute to clients falling out of the service system; thus, age is an important factor in a client's visiblity to the service system.

Older developmentally disabled persons in our times, comprise an invisible client group. The Report to Congress by the Comptroller General (1977) found that family and friends still provide over 50% of the services received by older persons at all impairment levels and over 70% of the services received by the severely impaired.

2) Disabilities Served. Just as age is a factor in determining who is and isn't being served, so is disability type. We estimated that all epileptics were being served in the 3-county area while persons with CP,

MR and autism were being served to a far lesser extent, in that order. This finding is exceptionally interesting in light of studies of social acceptability and the employment preferences vis a vis various disability types.

3) Attitudes. Yuker (1966) states that the social acceptability of a handicap appears to be related to the visibility of the disability, the extent to which it involves disfigurement, the extent to which handicaps are functionally limiting, and the extent to which social interaction involves feelings of discomfort or inability to predict the behavior of the handicapped person. The prevalence estimates in this paper reflect the expected population with epilepsy unaccompanied by any other disability, CP unaccompanied by any other disability, and substantial retardation both unaccompanied and accompanied by CP or epilepsy. We see that service availability, and perhaps social policy, follows the public's acceptability hierarchy towards the various disabilities. For example, epilepsy alone, especially if controlled by medication, is the least continuously visible handicap and one which may least interfere with the general quality of interaction. Cerebral palsy alone is a more visible handicap than epilepsy but one which does not necessarily lead to unpredictability of behavior or interferences in thought processes and quality of rational communication. In contrast, substantial retardation is usually perceived as interfering with thinking and communicating with others and as leading to unpredictability of behavior. Substantially retarded persons may also have the double burden (at an estimate of between 10-20%) of a disfiguring physical handicap. No studies were found that included attitudes toward adult autism.

Further, Yuker (1966) cites the Baxt, David, Jaffe, and Wang Study

(1959) which found that employers and employees rated epilepsy as having low acceptability and CP as having even lower acceptability. Although attitudes towards mental retardation were not evaluated in the Baxt et al. study, Yuker estimated that mental retardation would rank the very lowest among the disability types across all preference and acceptability studies. Thus, if social policy and service availability follows the public's stereotypic attitudes towards the various disabilities, and then we add age as a factor in the public's attitude, we see that AADD persons are in an unlikely position for becoming visible to service providers. Changes in the availability of services for this population may directly depend upon programs which change public attitudes.

Services Provided

One focus of this research project was to assess whether services provided were relevant to the needs of AADD clients. Our survey found that 57% of the serving agencies offered medical services; 54% offered information and referral services; 50% offered adult recreational services; and 43% offered staff development. These were the five most available services. Services with medium to low availability, though offered in relatively high frequency by the few agencies providing them, included: sheltered employment, diagnostic assessment, counseling, personal advocacy, income maintenance, and educational classes.

The availability of particular services also depended upon the type of agency providing the services. For example, many of the serving public agencies offered information and referral services. Far fewer public agencies offered other categories of service. Most nursing homes offered adult activities and medical services; however, AADD clients could also count on a nursing home's offering a number of other services. However, nursing homes constituted the largest percentage of agencies offering education classes, recreational activities, counseling, medical treatment, dental care, transportation, and personal advocacy. Thus, for AADD persons who are not living in nursing homes, medical treatment, recreational activities, and other services will not be as available as it appears when taking all agency service reports together.

Another consideration which needs to be taken into account in assessing which services are available to AADD clients involves the quality of service and the conceptual framework behind an agency's offering a particular service. For example, across nursing homes, a myriad of services are provided for AADD clients. Nursing homes, by their very nature would suggest this total care availability. However, many AADD clients are inappropriately placed in Minnesota's nursing homes for lack of alternative community placements via the deinstitutionalization process (Krantz, 1975). These nursing home experiences may closely mirror clients' previous institutional experiences--the continuation of the "sick role" expectations and continuation of total care, both of which discourage clients from negotiating community life (Gollay, et al., 1978). Further, the emphasis on medical care and recreational activities in nursing homes may meet only a few of the basic needs of inappropriately placed clients who were able to experience community living. Specifically, adult activities could on the one hand imply social interaction while on the other hand and more likely, it could imply watching television.

Public agencies also provide a myriad of services. Across public agencies, clients supposedly have access to services required by Public Law 94-103 Section 102. However, most public agencies in Minnesota primarily offered information and referral services. Despite all the information and referral, there was a dearth of transportation services to get clients from one agency to another.

Relevance of Services Provided

Having discussed the services available to AADD clients and the practical factors involved in understanding how available, in fact, these services were in Minnesota, we can assess the relevance of the services to the clients' needs. To do this let us posit some of the service needs arising from the experiences shared by many AADD persons of our day.

1) Deinstitutionalization. Deinstitutionalization is one such experience widely shared by AADD persons. Stedman (1977) says that deinstitutionalization is more than physical removal of a person from an institution and placement in a community: "It is often a state of mind and requires the re-socialization and preparation for reentry of a human being into a socialized community setting" (p. xii). Families of clients will need assistance in "undoing" their original decision to institutionalize their disabled members. The community will need assistance in overcoming both attitudinal and economic resistance to the client. The client must make the personal transition from institution to community life. The resocialization process must acknowledge the institutional experiences of the client in order to know what the client will need to learn.

Gollay, et al. (1978) found that most deinstitutionalized retardates came to accept new and realistic aspiratiions for themselves in the community, but that their families tended to have lower expectations of their capabilities. Job placement, job training, and community living training comprised the major service gaps from the clients' point of view

2) Loss of Caretaker. For AADD persons whose families kept them at home, the loss of primary caretaker, most often an aging parent, is an

experience more widely shared than institutionalization. The AADD person's almost total dependence upon the caretaker has been noted throughout the literature (Gollay, et al., 1978; DiGiovanni, 1978; Hofmeister, 1977; Kriger, 1975).

However, some of the issues relevant to deinstitutionalization are also relevant to AADD persons who have lost their primary caretaker. Given the era in which they were born and the centrality of the caretaker, these clients, too, must make a transition from a sheltered, perhaps isolated and infantalized lifestyle to other forms of community living.

IMPLICATIONS

What are the implications of this survey of Minnesota agencies? Services relevant to the needs specified by clients and their advocates; greater agency outreach to more AADD persons by the existing service agencies; more conceptual and practical coordination among service agencies; better record keeping practices by agencies to help generate a comprehensive data base on the prevalence, characteristics, and individual needs of their clients; programs geared to effect attitudinal changes among service providers and the public; quality control of community facilities and agencies, matched against the standards and goals of normalization, support systems for service providers; clear allocation of the responsibility for clients among agencies; and, perhaps, specific allocation of funds and clarification and elaboration of legislation in terms of this client group.

It is encouraging that the 1979 Minnesota State Plan is directing itself to many of the issues cited (Region V 1979 State Plan; Minnesota 1978 State Plan). Among the goals for 1979 stated in the Plan are:

advocacy work and needs assessment, identification and evaluation of the DD service network, investigating what conditions constitute inappropriate placement, planning and influencing activities, and public information activities. However, none of these goals are stated in terms of the AADD population.

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ANALYSIS OF SERVICES TO AADD PERSONS IN OHIO

Jeffry Ackerman

THE NORMALIZATION PRINCIPLE

The Normalization Principle and the AADD Population

One perspective from which to view the current state of affairs for the AADD persons is the principle of 'normalization.' This principle was first put forth by Bank-Mikkelson and later reformulated by Wolfsenberger (1972). Bank-Mikkelson, head of the Danish Mental Retardation Service phrased it as follows: "letting the mentally retarded obtain an existence as close to the normal as possible" (Wolfsenberger, 1972). In Wolfsenberger's terms normalization refers to "the utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible" (Wolfensberger, 1972).

In elaborating on the principle Wolfsenberger suggests that human service delivery systems should aspire to elicit and maintain behaviors and appearances as close to normal as circumstances permit. Not all persons being subjected to normalizing measures will remain or become normal, but the process is as important as the goal. The failure to implement the normalization principle has such potentially adverse affects, that it would appear to be society's obligation to adopt it.

The potential harm to the individual who is labeled deviant and cast aside, or who is placed into non-normalizing environments is enormous. Of great importance is the circularity between his own self concept, the way others react to him and the way he is likely to respond. Breaking that cycle requires a reduction in both the self-perceived deviancy of the individual and the perceptions of those with whom he interacts.

There are three distinct levels at which to implement the normalization principle: the person himself; his primary and intermediate social systems (family, peer group, classroom); and the social systems in which he lives (school systems, laws, mores). The first level includes teaching such things as social or adaptive skills in order to reduce the probability that the person will be viewed as deviant. The second level includes programs and policies which mainstream so called 'deviant' people. In the words of Wolfsenberger (1972):

> If we place impaired adults in a setting or grouping perceived to be specific to the aged (such as a nursing home), it is virtually inevitable that in the perception of many--if not most--observers, the younger impaired adults will be identified with the aura of hopelessness that is unfortunately imposed upon the aged ones. This means that it is much more adaptive to integrate one or a few aged persons among younger ones (in order to acquire their aura) than vice versa. (p. 38)

The third level includes social action such as redefining deviancy and fostering greater acceptance of behaviors or characteristics considered to be deviant.

The normalization principle is not without its critics. Mesibov (1976) has studied the concept and believes that it is not verifiable that it improves public attitude, and that it is not clear what is "normal." Throne (1975) disagrees with the principle on the grounds that if the goal for the developmentally disabled is normality, then extraordinary measures are needed, because the usual means are ineffective. These criticisms, however, seem to miss the major point of normalization. The experience of being viewed as deviant is potentially so devastating, that any experience of the process of normalization is welcome. The process itself can help to break the cycle of role expectation, role fulfillment, and reinforcement of role fulfillment through societal reaction to deviance

(Wolfensberger, 1972).

Until the past few years the normalization principle has not been widely applied to aged and aging developmentally disabled people. The recent surveys by Dickerson (1974) and those cited by Segal (1978) indicated a general lack of understanding, concern and interest for AADD persons. The deficiencies in service as elaborated by the Hamilton and Betts (1977) and Gordon (1977) highlighted the lack of potentially normalizing experiences. The Nebraska survey (Hitzing, 1978) clearly established that almost all of the nursing home residents surveyed could eventually function in community settings. They attributed the institutionalization to inadequate funding, inflexible and insensitive bureaucratic structures, to myths and sterotypes of deviance and to an uninformed and apathetic public.

Although there is conflicting evidence about the placement of previously institutionalized developmentally disabled persons in the community (Nihira & Nihira, 1975a; 1975b), there remains no doubt that community based programs are a viable alternative to dehumanizing institutional facilities. A large part of the evidence suggesting difficulty in adjustment is due to insufficient preparation for reintegration. After twenty-five years in the same institution, placement in the community becomes an unlikely alternative (Dickerson, 1974).

There is a very important parallel between the normalization principle for the aged and aging developmentally disabled and the "least restrictive environment" terminology of Public Law 94-142. The law addresses itself to the education of all handicapped children. It requires that they be placed in settings for their education as close to normal as they can adequately handle. It has led to the mainstreaming of children in the classroom and a change in the approach to special education (Paul, 1977). Furthermore, an individual education plan is to be provided for each individual until aged 25. Although parallel legislation exists for the older developmentally disabled person (Developmentally Disabled Assistance and Bill of Rights Act of 1975, Section 503 and 504 of the Rehabilitation Act of 1973) the impact has not been nearly as great. This seems attributable in large part to the fact that the aged and aging developmentally disabled people are not served within any one structure similar to the school system. In fact, there is no structure extant, to which they are all exposed, which can foster the development of the normalization principle. Community agencies which serve AADD persons should adopt the normalization principle, and it would seem appropriate for these service agencies to develop some type of individual treatment plan for their older developmentally disabled clients. Currently, the Individual Educational Plan ends where the state's mandatory special education ceases, usually age 21 to 25. It appears that a comparable plan has not been developed for the older individual in spite of legislation requiring it.

Human Service Organizations: The View from the Consumer

Is adoption of the normalization principle within the service delivery system for the AADD person possible? If the "most distinctive feature of human service organizations is that the relations between organization and client...are central to their structure,...these relations...become the most important tool with which an organization attempts to achieve its service goals." (Hasenfelf & English, 1975, p. 6) Hasenfeld goes on to develop a typology of organization-client relations.

The two dimensions of the typology are: 1) the degree of organizational interest in the client's personal biography; and 2) the compliance system employed by the organization which can be normative, utilitarian, or coercive. The cross classification of these two dimensions produces six types of organization-client relations as in Table I below.

Table I

A Typology of Organization--Client Relations

		Interest in Client's Biography	
		Limited	Extensive
Client's Compliance System	Normative	TYPE I University	TYPE II Treatment oriented mental hospital
	Utilitarian	TYPE III Medical clinic	TYPE IV Nursing home
	Coercive	TYPE V Police	TYPE VI Correctional institution

Hasenfeld raises several issues about these two dimensions. Organizations whose interest in the client's biography is limited run the risk of providing services which are unnecessary or of falsely attributing characteristics to an individual based on limited knowledge. On the other hand, organizations whose interest in the client's biography is extensive must constantly search for significant client attributes. They run the risk of missing or ignoring other pertinent and critical information which could enhance the nature of service delivery.

The compliance system also raises critical issues. A normative system is highly dependent on interpersonal relations between client and staff. A utilitarian system requires that the organization controls the necessary resources that are desired by the client. A coercive compliance system must ensure that the client will not escape the system (Hasenfeld, 197[illegible]

The AADD person will theoretically encounter any one of the six classifications as outlined in Table I when seeking or receiving services from a human service organization. Proponents of the normalization principle would clearly favor the normative type^{II} (high interest in interpersonal relations and high level of interaction and identification). This type would theoretically provide services which are geared to the individual's growth and development. Only those services which served that function would be offered to any given individual. An example of this type is the individual education plan (IEP) offered to developmentally disabled youngsters in the public schools. It remains to be seen, however, which type of agency the AADD person is most likely to encounter.

Juxtaposed with this typology of human service organizational structures is the newly emerging field of consumerism in mental health. In a paper presented at the Sixth World Congress of Psychiatry, in Honolulu, Beck and Marvit (1977) examine the public mental health delivery system. They conclude that the consumer: 1) is truly the forgotten person in the mental health field; 2) is relatively powerless and has been kept in the dark about what the helping profession do and how to assess the services they receive; 3) is further confused because of the difficulty in assessing, identifying and diagnosing what is wrong; 4) is forced, in the public arena, to accept whatever services and providers are available; and 5) is at the mercy of the human service system because there are no other options available.

In order to change the existing circumstances for the consumer it is suggested that they become part of the evaluation process. It is further recommended that the expectations of the consumers be compared with the outcomes of the service delivery. Finally, it is proposed that survey research and evaluation be conducted to determine the needs of the consumers. The suppliers have for too long been the sole determiners of the nature and quantity of services.

The Normalization Principle as Applied to Service Delivery

The normalization principle to the current service delivery system for the AADD population is replete with potentially insurmountable obstacles. It would require professionals to relinquish their dominance of a system in which they have virtually ignored the consumer. It would eliminate utilitarian or coercive human service organizations as defined by Hasenfeld (1975) for this population. It would require agencies to develop an interest in the client's biography extensive enough so that service plans would relate to specific needs. However, as long as consumers, practitioners and administrators are kept apart, normalization is impossible.

The basic tenet of the normalization principle is to utilize culturally normative means to establish or maintain as culturally normal behavior and characteristics as possible. Without a change in the power of the consumer this will not occur. As long as the service delivery system is unilaterally controlled by the agencies there can be little significant movement toward normalization. The circular pattern of treating the deviant as deviant, as defined by Wolfsenberger (1972), results in role expectations by the deviant (low self esteem, feelings of inadequacy) and role fulfillment (helplessness, withdrawal) which cannot be broken within the existing structure. This is demonstrated by the nature and scarcity of available services.

The existing service delivery system can be evaluated in light of Hasenfeld's typology to determine whether or not it is geared toward normalization of AADD persons.

Services presently offered reflect the agencies' attitudes toward normalization. If normalization, as defined previously, is an agency's goal, then services should be geared to promoting experiences enabling the client to function in the mainstream of society. Such services would include income maintenance, education, advocacy and treatment. Offering these services which are available to "normal" persons would reflect the agency's commitment to normalization. Other such specific services would include medical treatment, dental care, education and legal assistance. On the other hand, offering only services which decrease opportunities for normalization which are historically associated with deviancy would reflect a lack of commitment to normalization. Such specific services would include adult activities and sheltered employment.

The degree of agency concern for the individual client's biography can be inferred from the nature of its service offerings. Are they primarily administered on an individual basis and addressed to individual needs such as counseling and treatment, diagnosis, individualized habilitation and educational plans, and in-home services? Do they require an extensive understanding of the individual's biography in order to be satisfactorily administered as for example do guardianship, vocational counseling, and treatment. Or do they reflect a stereotypical view of

AADD persons, rather than highlighting unique needs and potential individual strengths? Such services as sheltered employment, adult activities, and globally administered counseling might reflect such a view.

Perceived obstacles to service are an additional source for information about the agency's service delivery system. Do the perceived obstacles reflect impediments to normalizing services such as client attitude, community sentiment and the individual needs of the client?

Finally the overall breadth of services available might be a useful index if there were a dramatic difference between service delivery to the AADD population and their younger counterparts.

The data to be thus analyzed was compiled through a questionnaire survey. This chapter analyzes the survey data collected in Ohio from the perspective of the principle off normalization.

METHODOLOGY

Sample Population

The questionnaires, definitions, and cover letters, along with a stamped, self-addressed return envelope were mailed to 137 Ohio agencies located in Columbus and Cincinnati, representing a university community and a principal urban area. After approximately four to six weeks, a follow-up packet was mailed to those agencies which had not responded to the original mailing. In spite of the limitations of sampling from a phone directory (outdated listings, lack of specific office addresses and/or zip codes), only 11 of the questionnaires in Ohio were returned with bad addresses. The overall response rate for the Region was 55%. The response rate for Ohio was 46%. Babbie (1973) has indicated that any response rate to a mailed questionnaire which exceeds 50% was sufficient for analysis and limited inference. Thus the response to the AADD questionnaire for the Region is sufficient to draw some general conclusions concerning service to AADD persons, but inferences for Ohio must be asserted with caution. The sample in Ohio consisted of federal, state, county, private, and city agencies in Cincinnati and Columbus (corresponding to the keywords). The estimated projected population of Ohio in 1980 is 11,675,000 (Statistical Abstracts of U.S., 1976, U.S. Dept. of Commerce, Bureau of Census). The combined population of Cincinnati and Columbus as of July 1, 1974 was over 2,400,000 (Bureau of Census). This represented over 20% of Ohio's population.

Data Analysis

The inability to estimate a sampling error for the survey, together with an uncomplicated questionnaire requiring only yes or no answers severely limited the kinds of statistical analysis which could be performed on the data. However, the dichotomous nominal variables (i.e., yes-or-no answers without provision for a graded response) which comprised the vast majority of the survey questions were treated as special cases of interval scales as suggested by Rosenberg (1968) and Hyman (1955). Although the data analysis was not limited to simple descriptive statistics, but general assertions about the level of services available to AADD persons in Region V would require a more comprehensive census of a sufficiently large and representative population. This, in addition to the large amount of missing data in the responses, dictated that frequency distributions and other simple descriptive statistics such as mean scores form the body of the analysis. However, analysis of variance and chi square values were also computed where suggested by the descriptive breakdown of the data.

Again, the precarious nature of the sample and the data itself placed real constraints on interpretation of results. Nonetheless, I have attempted to interpret the data from the survey so that it as accurately as possible reports the current state of affairs in services to older and aging developmentally disabled persons within Ohio. The reader should know in advance that, in those instances in which a number of factors could account for an observed phenomena, I have presented my own biases first, followed by any other possible explanations which arose from interactions with project staff.

RESULTS

Types of Agencies Providing Service

The breakdown of the 55 Ohio respondents by agency type and by percentage providing service was as follows:

Table I

AGENCY TYPE	# RESPONDING TO QUESTIONNAIRE	% OF SAMPLE (x/55)	# PROVIDING SERVICE	% OF TYPE PROVIDING SERVICE*	% OF ALL SERVICE PROVIDERS
Public	21	38.18	14	66.66	43.75
Private	9	16.36	5	55.55	15.62
Consumer	1	1.82	1	100.00	3.12
Nursing	16	29.09	10	62.50	31.20
Public School	3	5.45	1	33.33	3.12
Col U.	5	9.09	1	20.00	3.12
TOTALS	55	100.00	32		100.00

*: $\frac{\#\text{ providing services}}{\#\text{ responding}} \times 100$

Of the 55 agencies who responded to the questionnaire, 32 or 56.2% reported that they were providing service to AADD clients.

Public agencies were most likely to provide service (66%)[1]; however, nursing homes and private agencies were serving at approximately the same percentage. Colleges or university agencies and the public schools were least likely to provide service with 20% and 33-1/3% service rates respectively. The consumer agency was not considered because only one such agency responded.

It should be noted for reference in reading the results of this study that three types of agencies comprised the greatest part of the sample. Public agencies and nursing homes accounted for over 67% of the sample; public agencies, nursing homes, and private agencies together accounted for 29 of the 32 respondents or 93.6% of the sample.

Despite the above, in analyzing the 32 agencies who reported serving the AADD population, no statistically significant difference was found by type of agency as to whether or not service was provided. Although, the data indicated a strong trend toward no service by public schools or by colleges or universities, difference was not statistically significant inasmuch as the small N for these categories required greater magnitudes of difference. Nursing homes, public and private agencies were very similar in the percentage providing service to this population.

Similarly, source of funding made no statistically significant difference as to whether or not service was provided. Regardless of the source of funding (federal, state, county, private, or special) the likelihood of any given agency providing services to the AADD was essentially the same.

Extent of Services Provided in Area Surveyed

Although extrapolation of the data was necessary for the following analysis, these extrapolations were the most conservative ones possible.

Number of AADD Clients Receiving Service. Of the 55 agencies in the areas surveyed, 32 reported they were serving AADD clients. Eighteen of these 32 were able to categorize by age. This is represented in Tables II and III. A total of 1950 clients were reported by the 18 agencies who were able to categorize by age.

Table II

Number of AADD Clients Served by Age Range and Agency Type

AGE RANGE	AGENCY TYPE						
	N=5 PUB	N=2 PRI	N=1 CON	N=8 NURS	N=1 SCH	N=1 COL/U	N=18 TOTAL
35-54	358	494	169	14	5	1	1041
55-64	21	349	1	27	3	0	401
65+	67	291	0	148	2	0	508
TOTAL	446	1134	170	189	10	1	1950

Table III

Percentage* of AADD Clients Served by Age Range and Agency Type

AGE RANGE	AGENCY TYPE						
	N=5 PUB	N=2 PRI	N=1 CON	N=8 NURS	N=1 SCH	N=1 COL/U	N=18 TOTAL
35-54	34.5	47.5	16.3	.013	.004	<.001	100%
55-64	5.2	87.8	.002	6.7	.007	0	100%
65+	13.2	57.3	0	29.1	.01	0	100%
TOTAL	22.9	58.2	9.0	10.1	1%	0	100%

*: # of clients served by given agency within age category x 100
# of clients served by all agencies [illegible]n age category

Potential Number of AADD Clients Lving in Area Surveyed. If the 14 agencies who said yes to providing service but who were unable to categorize by age are assumed to serve AADD clients at the same rate as the 18 agencies, an additional 1517 individuals can be projected as served.

Total reported served	1950
Extrapolated total	1516

Total served by agencies returning questionnaires	3466

If it is further assumed that the 71 agencies who did not return the questionnaire were providing service at the same rate, we would have an additional 4332 served according to the following calculations.

Total reported served by 18 agencies able to categorize by age	1950
14 agencies reported serving population but not able to categorize by age 14 agencies x 108.3 (average service rate of agencies able to categorize) =	1516
71 agencies not responding; assume 56.2% of 71 would provide service = 40 agencies 40 agencies providing service at 108.3 (base rate) 41 x 108.33 =	4332
90 nursing homes in area that were not surveyed at 56.2% service rate = 50 nursing homes 50 x 24 (average number served for nursing home) =	1200

Maximum possible number of 35+ AADD persons served =	8998

The grand total of AADD population served in Cincinnati and Columbus, including 90 nursing homes not surveyed, was 8998 persons. The projected maximum number of persons 60+ among this 8998 was 3830 according to the following calculations.

Total 65+ reported served	508	
Total 55-64 reported served: 401; assuming evenly distributed across this age category 200 persons would be age 60-64	200	
		708
14 agencies reported serving population but not able to categorize by age 14 x 39.3 (average service rate of 18 agencies able to categorize) =		550
71 agencies not responding; assume 56.2% of 71 would provide service = 40 agencies 41 x 39.3 =		1572
90 nursing homes in area that were not surveyed at 56.2% service rate = 50 nursing homes 50 x 20 (average number 60+ served in nursing homes) =		1000
Maximum number 60+ served =		3830

The combination of U.S. Dept. of Commerce Bureau of Census (1976) and the Economic Manpower Corp. (Schpok, 1977) yields the data in Table IV about the potential number of aged and aging developmentally disabled population in Cincinnati and Ohio reached by the survey. (Calculations appear below.) This includes adjustment of figures to account for 80% of nursing homes not reached in the survey.

The total estimated population of Ohio for 1980 is 11,675,000. The combined population of Cincinnati and Columbus, as of July 1, 1974 is 2,443,000 (Statistical Abstracts of U.S. 1976, U.S. Dept. of Commerce, Bureau of the Census). Utilizing the accepted percentages below as documented by Bureau of Census and Economic Manpower Corp. gives the following data:

41.5% of population is 35+ (.415 x 2,443,000) =	1,013,845
15.2% of population is 60+ (.152 x 2,443,000) =	371,336

4.3% of population 35+ is potentially

developmentally disabled (.043 x 1,013,845) = 43,595
2.08% of population 35+ is potentially severely developmentally disabled (.0208 x 1,013,845) = 21,088

4.3% of population 60+ is potentially developmentally disabled (.043 x 371,336) = 15,967
2.08% of population 60+ is potentially severely developmentally disabled (.0208 x 371,336) = 7,723

60% of potentially severely developmentally disabled are served outside institutions
40% of potentially severely developmentally disabled are served inside institutions

Assuming randomness of the survey, it is possible to extrapolate the following:

The potentially served developmentally disabled individuals reached by this survey are the figures listed above less the 80% of nursing homes not included in the survey.

This reduces the possible number of AADD reached by the area surveyed by 6748 for 35+ and 2471 for 60+, yielding:

Number of DD 35+ potentially reached by survey = 36,847
Number of SEVERE DD 35+ potentially reached = 14,340
Number of DD 60+ potentially reached by survey = 13,496
Number of SEVERE DD 60+ potentially reached = 5,252

Table IV

Potential Number of AADD Clients in Area Surveyed

AGE	POPULATION		
	Overall	DD	Severe DD
35+	1,013,845	36,847	14,340
60+	371,336	13,496	5,252

Maximum Possible percentage of AADD Clients Served. Even with the most generous estimates possible, 24% or 8998 of the 36,847 potentially DD age 35+ were receiving service in the area surveyed. If all those receiving service were assumed to be severely disabled and age 35+, only 63% or

8998 of the 14,340 persons were receiving service in the area surveyed.

Even with the most generous estimates possible only 28% or 3830 of the potential 13,496 disabled age 60+ were receiving service in the area surveyed. By the same method of estimation, even if all service recipients were assumed to be over 60 and severely disabled then only 73% were receiving service in the area surveyed.

Table V

Number of DD Receiving Service in Columbus and Cincinnati Relative to Potential DD in the Area

	POTENTIAL NUMBER OF DD REACHED BY SURVEY	HIGHEST POSSIBLE NUMBER OF DD RECEIVING SERVICE	HIGHEST POSSIBLE % OF DD RECEIVING SERVICE
DD 35+	36,847**	8,998#	24%#
Severe DD 35+	14,340**	8,998*	63%*
DD 60+	13,496	3,830#	28%#
Severe DD 60+	5,252	3,830*	73%*

*: Assuming that all those receiving service are severely developmentally disabled

#: Necessarily includes those who are severely developmentally disabled

**: Includes DD over 60+

Table V indicates the highest possible number of DD individuals who could have been receiving service. It is highly unlikely that the generous assumptions made about non-respondents were accurate. Hence, probably fewer AADD clients were actually receiving service. It is also likely that the number of DD persons was underestimated. But even allowing the most generous assumptions, there was still a marked discrepancy between the potential number needing service and those projected as receiving service. It should also be noted that receiving services only meant that services were delivered. It says nothing about the nature and quality of those services.

Specific Services Provided by Agencies Surveyed

Of the 55 agencies which responded, 32 or 56.12% checked off those services which they then delivered to aged and aging developmentally disabled individuals. The services, the type of agencies providing these services, and the frequency of each service are summarized in Tables VI - X.

An analysis of variance yielded no statistically significant difference in service provision by agency type, but analysis of Table VI percentages yielded useful information and trends.

Table VI indicates a fairly broad range of services was offered to AADD clients in Ohio. However, the most extensively offered services were available from fewer than 60% of the agencies (see Table VII). Those least extensively offered (see Table VIII) were available from fewer than 19% of the agencies.

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Table VI

and % of Agencies Providing Specific Services by Agency Type

	N = 15		N = 5		N = 1		N = 9		N = 1		N = 1		N = 32	
	PUBLIC		PRIVATE		CONSUMER		NURSING		PUB.SCH.		COL.U.		TOTAL	
SERVICE	#	%	#	%	#	%	#	%	#	%	#	%	#	%
Education	7	46.7	1	20	1	100	2	22.2	1	100	1	100	13	40.7
Voc Couns	5	33.3	1	20	1	100	1	11.1	1	100	0	0	9	28.2
Shelt Emp	4	26.7	1	20	1	100	1	11.1	0	0	0	0	7	21.9
Adult Act	9	60.0	0	0	1	100	7	77.8	0	0	0	0	17	53.2
Info/Refer	10	66.7	4	80	1	100	2	22.2	1	100	1	100	19	59.5
Couns/Treat	7	46.7	1	20	1	100	1	11.1	0	0	0	0	10	31.3
Med/Treat	2	13.3	3	60	0	0	6	66.7	0	0	0	0	11	34.4
Diagnostics	3	20.0	2	40	1	100	3	33.3	1	100	0	0	10	31.3
Staff Dev	7	46.7	3	60	0	0	2	22.2	0	0	0	0	12	37.6
Dental	1	6.7	0	0	0	0	1	11.1	0	0	0	0	2	6.3
Transport	6	40.0	1	20	1	100	5	55.6	0	0	0	0	13	40.7
Guardianshp	3	20.0	1	20	0	0	2	22.2	0	0	0	0	6	18.8
Advocacy	3	20.0	0	0	1	100	2	22.2	0	0	0	0	6	18.8
InHome Serv	5	33.3	0	0	0	0	1	11.1	0	0	0	0	6	18.8
Legal	2	13.3	0	0	0	0	0	0	0	0	0	0	2	6.3
Foster	1	6.7	0	0	0	0	0	0	0	0	0	0	1	3.1
Oth Res Car	2	13.3	1	20	0	0	5	55.6	0	0	0	0	8	25.0
Inc Maint	4	26.7	0	0	0	0	2	22.2	0	0	0	0	6	18.8
Other	3	20.0	4	80	1	100	2	22.2	0	0	1	100	11	34.4

Table VII

Most Frequently Offered Services Across All Agencies

SERVICES	% OF AGENCIES OFFERING (32 Responding)
Information/Referral	59.5
Adult Activities	53.2
Transportation	40.7
Education	40.7
Staff Development	37.6

Table VIII

Least Frequently Offered Services Across All Agencies

SERVICES	% OF AGENCIES OFFERING (32 Responding)
Foster Care	3.1
Legal Assistance	6.3
Dental Care	6.3
Guardianship	18.8
Advocacy	18.8
In Home Service	18.8
Income Maintenace	18.8

Table IX

Frequently Offered Services By Agency*

PUBLIC (15 responding)		PRIVATE (5 responding)		NURSING (9 responding)	
Service	%	Service	%	Service	%
Info./Referral	66.7	Info./Referral	80.0	Adult Activ.	77.8
Adult Activ.	60.0	Medical Treat.	60.0	Medical Treat.	66.7
Staff Develop.	46.7	Staff Develop.	60.0	Transportation	55.6
Counsel./Treat.	46.7	Diagnos. Assess.	60.0	Other Res. Care	55.6
Education	46.7			Diagnos. Assess.	33.3

* Colleges or universities, public schools, and consumer agencies excluded because N=1

Table X

Least Frequently Offered Services By Agency*

PUBLIC (15 responding)		PRIVATE (5 responding)		NURSING (9 responding)	
Service	**%**	**Service**	**%**	**Service**	**%**
Dental	6.7	Adult Activ.	0	Legal Services	0
Foster Care	6.7	Advocacy	0	Foster Care	0
Other Res. Care	13.3	Legal Services	0	In Home Services	11.1
Medical Treat.	13.3	Foster Care	0	Dental	11.1
Legal Services	13.3	Income Maint.	0	Voc. Counseling	11.1

* Colleges or universities, public schools and consumer agencies excluded because N=1

Although there was no statistically significant difference by agency as to type of services provided, there were distinctly different trends as to least and most frequently furnished services as noted in Tables IX and X. Information/referral was provided most frequently by both public and private agencies, whereas more nursing homes offered adult activities than any other service. Medical treatment was one of the services most frequently provided by nursing homes and private agencies but one of the least frequently provided by public agencies. Public agencies were the only one of the three types to offer education and counseling treatment most frequently, whereas nursing homes were the only ones to offer diagnostic assessment most frequently.

Other important findings about the nature and type of services provided were:

- only one agency (3.1%) provided foster care;
- only two agencies (6.2%) provided dental services or legal assistance;

- six agencies (18.8%) offered guardianship, advocacy, income maintenance, or in-home service;
- eleven or fewer agencies (less than 35%) agencies offered vocational counseling, sheltered employment, counseling and treatment, medical treatment, diagnostic assessment, other residential care of other services;
- adult activities and information/referral were the only services provided by more than 50% of the agencies; and
- the average percentage of agencies providing services across all services was less than 27.8%.

Service Provision by Category

Although there are literally hundreds of potential categorizations of the available services, five appeared to be relevant to the issues addressed earlier and also to lend themselves to an analysis of the normalization principle. These categories were: 1) direct services administered on an individual basis; 2) direct services requiring an extensive understanding of the individual's case history to be delivered satisfactorily; 3) direct services enhancing or promoting opportunities for experiences in the mainstream of society; 4) direct services provided to "normal" persons on a regular basis; and 5) direct services historically associated with developmental disability.

There will be some overlap, but total figures allow comparisons between categories and against any individual service area. The categorizations also address the questions and issues outlined earlier by breaking the available services into groupings which can then be analyzed in terms of the normalization principle. One can ascertain trends and tendencies from the data, which can in turn generate testable hypotheses for future researchers.

Table XI

CATEGORY	SERVICES INCLUDED	TOTAL % OF AGENCIES OFFERING SERVICE N=22	% OF PUBLIC AGENCIES N=15	% OF PRIVATE AGENCIES N=5	% OF NURSING HOMES N=9
Entire gamut of services available	All	27.8	28.6	24.2	26.3
Direct services primarily administered on an individual basis and addressing individual needs	Vocational counseling, counseling, medical treatment, diagnosis, dental, transportation, guardianship, in-home services, legal, foster care	22.3	23.3	18.0	22.2
Direct services requiring an extensive understanding of individual's biography to be delivered satisfactorily	Counseling / treatment, diagnostics, foster care, guardianship, vocational counseling	22.5	25.3	20.0	15.5
Direct services enhancing or promoting opportunities for experiences in mainstream of society	Education, counseling / treatment, advocacy, income maintenance	27.3	35.0	10.0	19.4
Direct services available to "normal" persons on a regular basis	Medical treatment, dental, education, legal	21.9	20.0	20.0	25.0
Services historically associated with deviancy	Sheltered employment, adult activities, counseling / treatment, vocational counseling	33.6	44.2	15.0	27.9

Although the categories are somewhat arbitrary, they do reflect "common sense" associations. Furthermore, although these associations were been systematically checked, they were scrutinized by other project staff and found acceptable. The inferences that one can make are necessarily limited by this fact. The descriptive statistics alone indicated only minor differences across agencies. Nor did analyses of variance yield statistically significant differences among the different agency types by these categories. However, the data suggest some trends.

The percentage of agencies providing services in all categories which could be considered normalizing or showing high interest in the individual were smaller than the percentage of agencies providing all services. The percentage providing services generally associated with deviancy, however, exceeded the percentage for all other categories. The public agencies were most likely to be providing services associated with deviancy and private agencies least likely. Just the opposite was true for services enhancing or promoting opportunities for mainstreaming experiences.

In general a higher percentage of public agencies provided all of the various services, with nursing homes next, followed by private agencies, but the trend for all three agency types was to provide fewer services that enhance normalization or individual development.

Funding Source and Services Provided

In several instances chi square analyses and analyses of variance test statistics yielded significant differences between funding source and whether or not specific services were offered. Only where the level of significance for both test statistics exceeded $p < .05$ was the difference considered statistically significant. The statements below are limited to results from these tests of statistically significant differences.

Agencies receiving federal funding were no more likely to provide any given service than those who were not receiving federal funding.

Agencies receiving state funding were more likely to provide medical treatment, vocational counseling, sheltered employment, adult activities, and in-home services than those agencies which did not receive state funding.

Agencies receiving county funding were more likely to provide vocational training, sheltered employment, counseling, transportation, advocacy, in-home services and adult activities than those agencies which did not receive county funding.

Agencies receiving private funding were more likely to provide vocational training than those agencies which did not receive private funding.

Agencies receiving special funding were more likely to provide counseling than those agencies which did not receive special funding.

With the exception of those services elaborated in the above statements, there were no statistically significant relationships between funding source and the provision of all other services.

Perceived Obstacles to Serving AADD Clients

The responses to the question about obstacles to service delivery are depicted in Tables XII and XIII by agency type and funding source. Forty-six (46) of the 55 agencies which returned the questionnaire provided the data.

There was no statistically significant difference by agency type as to obstacles impeding service delivery. In fact the similarity of reported obstacles was striking. All three agency types analyzed reported inadequate funds, attitude of community toward client, and lack of staff training and development to be among the five most frequently encountered obstacles.

Nor did funding source influence the obstacles reported. Not only was there no statistically significant difference between source of funding and reported obstacles but the lists were almost identical. The five obstacles reported by the greatest percentage of agencies were:

Table XII

Obstacle	% of Agencies Reporting Obstacle
Inadequate funds	61
Transportation	50
Staff training and development	37
Attitude of community toward clients	35
Lack of community support service	35

The five least frequently reported obstacles by all agencies were:

Table XIII

Obstacle	% of Agencies Reporting Obstacle
Certification and on Licensing	15
Difficulty of maintaining staff	15
Client attitude	17
Difficulty funding qualified staff	22
Severity of client handicap	24

Only transportation and inadequate funds were perceived as obstacles by more than 50% of the agencies. No other obstacles were viewed as problematic by more than 37% of the agencies.

Although inadequate funds was listed as the major obstacle, the agencies are unable to specify what they would do with additional funds. The two most frequent responses to the question "If additional staff and funds were available, what other services would you provide for AADD?"

were "none" and "more of the same."

Although there were some slight variations in percentage of each agency type reporting a given obstacle, the fact that the major problems were virtually identical is noteworthy. The only major obstacle not included by nursing homes was transportation (for obvious reasons). It appears, then, that the five most frequently perceived obstacles were virtually the same across agency type and funding source.

DISCUSSION

Caution must be exercised in drawing inferences and conclusions from the survey, but perhaps the following discussion will increase the reader's awareness of the plight of AADD people and encourage research on the delivery of service to this population.

Number of AADD Persons Served

Although it was possible to hazard some specific inferences about the relationship between the number served and the number of AADD potentially living in the surveyed area, there is still a nationwide lack of demographic data and information about this group (Dickerson, 1974; Thomas, 1978; Segal, 1978; Hitzing, 1978). Furthermore, most available demographic information is confounded by unclear definitions and by inconsistent identification criteria (Thomas, 1978). This was true of the demographic information about AADD persons in Ohio.

Although 56.2% of the respondents reported that they were providing services to the AADD population, only 28.1% could categorize the clients by age and/or disability type. The excuse most frequently given was that records were not maintained by these categories. This weakens the reliability of the data as to whether or not service was actually provided to AADD. The logic reduces to, "How do you know you are serving the AADD clients if you don't have them categorized by age or disability?" There was probably a fair degree of misinterpretation as to the identity of these clients (Hitzing, 1978), and this means that the data must be read and intepreted with caution.

The inferences from available data indicated that a high number of AADD clients were not being served in the region surveyed: at least 50% of these clients over 35 were either not properly identified or not properly served. In some age categories the percentage not being served was as high as 75%. Unsophisticated identification techniques, the tendency for home caretakers to bear the responsibility, the lack of understanding of the definition of AADD, and the absence of a power base for AADD persons are but a few of the suggested reasons that have been suggested (Thomas, 1978). Suffice it to say that the survey data indicated that literally thousands of AADD persons were living in Cincinnati and Columbus with special needs that were not being met. It is not unreasonable to infer that throughout the state at least similar percentages of AADD people were not being served.

It should also be borne in mind that even though 1950 AADD clients were reported served by the 18 responding agencies, this total may have been greatly inflated. Two private agencies accounted for 1,134 of the 1,950 clients. That meant that 11% of the agencies accounted for 58% of the clients. If these two agencies were removed from the sample, only 716 AADD persons would be served by the remaining 16 agencies, sharply reducing all extrapolated figures on the population served.

From is every indication, AADD clients were being overlooked. The projection for increasing numbers of AADD clients in the future (Segal,

1977) makes the lack of services and identification increasingly critical. Furthermore, the mere fact that there was such a great deal of confusion about this group reinforces the notion that they are an "invisible client." In order to establish some reasonable identity the agencies charged with serving this group, should at the very least be able to recognize them as such. The survey indicates that in many cases they could not. Without this recognition it is highly probable that services to which these individuals are entitled were not available. Inasmuch as society has not integrated this particular group of "deviants" into the mainstream, they are highly dependent on the agencies designed to serve them. The overall level of uncertainty as to identification and responsibility leaves this group with very little recourse. The likelihood is that each individual needs to fend for himself. To do so requires the ability to sort out from the maze of agencies the ones that can help, but the agencies themselves appear uncertain as to whom they are supposed to serve.

Choosing a Service Agency

The composition of service providers by agency type is such that consumer agencies, public schools, and college and universities combined accounted for less than 10%. It is reasonable to conclude that this group of agencies was generally ignoring AADD people. Among the three remaining agency types (Public, Private and Nursing Homes), the percentage serving AADD people was about 60%. However, nursing homes must be considered a special case in as much as they accounted for so few clients. One can infer that it was only the private and public agencies which were, as a rule, serving the specific interests of defined AADD clients. This would further reduce the number of agencies actively providing service.

Viewed in this light the greatest opportunity for reaching and appropriately serving AADD clients appears to be through private and public agencies. They were reaching the largest number (over 75% of the 1950 clients reported served) and were providing service at 66.6% and 55.5% respectively. Although nursing homes reported service provision at 62.5%, the consideration noted above must be taken into account along with other psychological factors associated with such placement.

Placing an AADD person in a nursing home facility has potentially serious harmful effects (Zigler & Balla, 1977). This has been documented in a recent study at the University of Nebraska (Hitzing, 1978). They concluded that a vast majority of AADD persons would fare much better in a different setting. Nursing homes were found not to be geared to the unique needs of those with developmental disabilities. Fully 50% of the residents could have been placed immediately into existing community services. The remainder could have been integrated into the community with some individual help.

But the most striking finding was that a variety of human services were denied the nursing home resident and that the likelihood of growth and productive activity was virtually unattainable (Hitzing, 1978).

This survey finding supports the contention that the best interests of the AADD population are more likely to be served in settings other than nursing homes. Our survey suggested that in Ohio this would mean a public or private agency.

The data did not yield sufficient information to draw any far reaching conclusions. One can safely reaffirm, however, that the aged and aging developmentally disabled person in Ohio had no human service system which paralleled the schools for his younger counterpart. Left to fend for himself, the AADD person was more likely to encounter organizations which were, in Hasenfeld's (1975) typology, utilitarian or controlling. The "misplacement" of many AADD persons in nursing homes was a prime example of this.

Funding Source and Service Delivery

In evaluating the data on services offered by funding source, some statistically significant and potentially worthwhile information appeared. In several service categories the likelihood that a given agency would offer a given service was directly related to whether or not it received state funding and/or county funding. This was the case with over one-third of the service categories. Although there was no special pattern to the nature of the service, the results indicated a relationship worth considering. It may be that accountability and quality control were increased when county and/or state funding was involved. Conversely, the data clearly indicated that whether or not federal funding was received made absolutely no difference as to whether or not any of the services were offered. The clear implication is that providers of state and county funding may be able to influence the type and extent of services delivered. If federal funding had no effect on the service system, it would seem that the federal government was not adequately enforcing the standards of its current legislation.

The Gap Between Services Available and Unmet Needs

In a review of recent surveys of the service needs of the AADD population, Segal (1977) reported a wide range of unmet needs. Although there were some differences in the specific needs identified, the general picture was similar: a paucity of available services and a host of unmet needs.

Building on this information, the current survey set out to determine the general availability of services in Ohio by examining Columbus and Cincinnati, and then to compare the results with the conclusions of the other surveys. The nature and level of services were analyzed in view of Hasenfeld's typology and the principle of normalization as addressed in the overview. Finally, service delivery by agency type was compared.

The overall picture that emerged from the data was a lack of coherence and consistency in service delivery and a generally low level of service offerings by all agency types.

The least frequently available services included foster care, legal assistance, dental care, guardianship, in-home service, and income maintenance. All of these services would enhance the client's opportunity to live in the community. All six of the least provided services would contribute to the independent functioning of AADD persons. However, these services tend to require a greater investment in the unique needs of the individual and a greater commitment to the normalization of AADD persons. They were the least likely to be offered.

On the other hand, the most frequently provided services were information/referral, adult activities, transportation, education, and staff development. Most of these are services can be offered at the agency site and require a minimal amount of client-staff interaction (Hasenfeld, 1975). None of them require the client to interact with members of the "normal" population.

Not only were AADD persons faced with limited services, but the services offered did not necessarily relate to their needs. The Temple University study (Gordon, 1977) identified ten unmet needs. Services relating to seven of these unmet needs were offered by fewer than 20% of the agencies offering service in Ohio. Of the unmet needs identified by the Chicago study (Hamilton & Betts, 1977), only transpotation was being provided by more than 50% of the agencies in our survey. The other five unmet needs were either not provided for at all, or were provided for by less than 33% of the service agencies.

Services representing opportunities for normalized functioning were provided by even fewer agencies in Ohio than were providing for the unmet needs listed by Gordon and by Hamilton and Betts. The overall service delivery system mitigates against integration into the society, and within that system, services geared to normalization seem to be offered less frequently. Services associated with interpersonal encounters between client and worker were the least frequently offered of all.

Even accounting for methodological limitations and some manipulation of the service categories, the data still points to the conclusion that adequate services were not being provided and that those that were being provided reflected the bias of the agency rather than the needs of the client. The trends in the percentage figures in these service categories reinforced the claim that indeed the AADD client was not receiving services which would normalize his functioning or stimulate his individual growth.

The AADD person confined to institutions and nursing homes received the services available within those structures. As noted earlier, these tended to be controlling or utilitarian. Those living in the community do not appear to fare much better. Hamilton and Betts (1977) found that less than 9% of the AADD persons in Chicago were employed. Gordon (1978) has pointed out that once AADD persons leave school "they no longer exist as a member of a significant consumer group requiring specialized services."

The service delivery system reflects the view of the society toward this group. Society, has chosen to deal with this group by isolating it. The agencies funded to serve this group apparently determine the nature of services apart from the desires, expectancies and needs of the consumer (Beck & Marvit, 1977). Nothing in the service delivery data for Ohio indicated a commitment to normalizing the AADD person. Agencies providing services showed limited interest in the background and biography of the client. The services, as a whole, were clearly not normalizing as described in Hasenfeld's (1975) typology.

The gains which younger developmentally disabled people have made occurred only after they established a firm power base (Cohen & Sweeney, 1977). This resulted in legislation which changed their relationship to society (Rhodes & Sweeney, 1977). Any dramatic change in services to AADD persons will require a similar process. The survey indicated that scarce services, confusion over definitions, and lack of concern for the individual's normal functioning have hindered even the first steps in this process.

Perceived Obstacles to Serving AADD Persons

There were virtually no differences among agency types or their funding sources in perceived obstacles to serving AADD persons. The only important exception was that finding qualified staff was one of the least frequently listed obstacles of the total group but it was the third most frequent obstacle for nursing homes. This implies that the training needs of nursing homes are high and reinforces the notion put forth earlier that nursing homes are not a good place for most AADD persons.

Although inadequate funds was obstacle number one for all agencies, most said they would either do nothing different with more money or more of the same. In other words, more money would not influence the nature of their services. This, coupled with the absence of any relationship between the agencies' funding source and whether or not they served AADD persons, suggests the agencies had a limited perspective. Apparently they saw their current pattern of service delivery as acceptable.

Transportation was also frequently cited as an obstacle to service delivery. This highlights the frustration shared by the agencies and their clients. If the AADD clients cannot get to the site, even the most sophisticated services possible are meaningless (Gordon, 1978). That it is a strongly recognized obstacle underscores its impact on service delivery.

With the exception of these two obstacles, most others do not appear to be particularly significant to the agencies. The remaining ten listed obstacles are viewed as major problems by less than 37% of the agencies. One half of the listed obstacles are viewed as problems by less than 20% of the agencies surveyed. Such obstacles as community attitude and support services and staff training and development are among these. It follows logically that if there is no commitment to providing services which would enhance the opportunities for normalizing functions then obstacles such as community attitude and staff competency would not be important. This is apparently the situation in Ohio.

In summary, the most striking findings from the data are that: 1) there is a fair degree of misinterpretation as to the identity of these clients; 2) there are literally thousands of AADD persons in the sample area with special needs that are not being met; 3) the quantity of services offered is extremely limited; 4) the types of service do not relate to the needs of the AADD persons as identified in other surveys; 5) there is nothing contained in the entire service delivery data which indicates a commitment to the normalizing of this population; 6) the major obstacle perceived by the agency to more effectively meeting service needs is inadequate funding; and 7) obstacles which would impede normalizing experiences are not perceived as major problems.

It would appear, then, that in order to resolve the plight of the AADD individual it is necessary to increase the community's awareness of its obligations and responsibilities to this population. Perhaps this would lead to the development of services which are consistent and relevant to the needs of the AADD population. Ideally these services would not only facilitate normalizing experiences, enabling this group to be part of the mainstream of society, but would also reflect the unique needs of each individual.

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ANALYSIS OF THE WISCONSIN DATA

Anthony W. Jackson

INTRODUCTION

The purpose of this study is twofold: to investigate community support services for Wisconsin aging/aged developmentally disabled (AADD) persons and to consider the implications of these present findings for future social policy.

Services for AADD citizens are provided by human service organizations. Hasenfeld (1974) defines human service organizations as ". . . organizations whose explicit purpose is to shape, change, and control (client) behavior, as well as confirm or redefine his social and personal status" (p. 1). Many human service organizations such as welfare agencies, nursing homes, hospitals, schools, etc., have been concerned with individuals whom society has labeled "deviant." Deviant individuals are those who are perceived as being significantly different from others in some important negative aspect (Wolfensberger, 1972). Many human service organizations see their clients as deviant and have developed an "ideology of deviance" based on the notion that deviant individuals are deficient, inferior persons. Consequently, the emphasis in many human service organizations has been toward the segregation of deviant individuals from the mainstream of society or even their destruction (Wolfensberger, 1972).

In contrast, there exists an ideology which accepts the client as different but not deviant, that is, not deficient. It has its theoretical basis in a belief that every man and woman has within them a unique "human potential." Wolfensberger (1972) and Nirje (1976) have described an alternative to deficiency-based service ideologies and have called it "normalization." Nirje defined the normalization principle as follows: "making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society." Wolfensberger (1976) describes it as a "developmental model," noting:

> The developmental model takes an optimistic view of the modifiability of behavior, and usually it does not invest the differentness of the retarded person with strong negative value. Even if severely retarded, he is perceived as capable of growth, development, and learning. (p.44)

It is clear that the normalization ideology is a "growth motivated" ideology. It is a theory of the way human services should be provided to deviant individuals, which emphasizes "self-actualization" (Maslow, 1968) regardless of the severity of the impairment. "The application of the normalization principle will not 'make retarded people normal,' but it will make their life conditions as normal as possible, respecting the degrees and complications of the handicap . . ." (Nirje, 1976, p. 2).

What of the AADD person; is he perceived as deviant? Wolfensberger (1976) notes: "The retarded person, being handicapped and often multiply stigmatized, is deviant by definition" (p. 43). Furthermore, Farber (1968) classifies the aged as part of the American "surplus population"; individuals considered deviant not solely because they possess unusual characteristics but because no productive role exists for them in our competitive, achievement oriented society.

To be aged and handicapped is therefore an unfortunate situation of "double jeopardy" (Dickerson, 1974). What remains to be seen is: What is the current status of services for this group of deviant individuals in Wisconsin? However, before this is done it is necessary to define aging/aged developmentally disabled.

AGING/AGED DEVELOPMENTALLY DISABLED: A DEFINITION

In the area of developmental disabilities, federal law (P.L. 94-103) defines who should be considered developmentally disabled. The law states:

> 7. The term "developmental disability" means a disability which:
>
> A. 1. is attributable to mental retardation, cerebral palsy, epilepsy, or autism.
>
> 2. is attributable to any other condition of a person found to be closely related to mental retardation because such condition results in similar impairment of general intellectual functioning or adaptive behavior to that of mentally retarded persons or requires treatment and services similar to those required for such persons; or
>
> 3. is attributable to dyslexia resulting from a disability described in clause 1. or 2. of this subparagraph;
>
> B. originates before such person attains age eighteen;
>
> C. has continued or can be expected to continue indefinitely; and
>
> D. constitutes a substantial handicap to such person's ability to function normally in society.

As there continues to be some question as to how best to operationalize the intent of the legislated definition (e.g., the National Task Force on the Definition of Developmental Disabilities), the legal definition of developmental disabilities will be used throughout this study.

However, "aging" and "aged" are more difficult terms to define, especially for developmentally disabled persons. Thomas (1978) identifies three dimensions of human functioning: biological, sociological, and psychological, which can be used as indices of the aging process and must be considered in the formulation of an operational definition of aging.

Kriger (1975) states that:

> In general, then, we find that due to a combination of both physical and social factors, a state of dependence exists for the retarded which is similar to that which defines the onset of old age in normal persons, but this dependence can be found in retarded persons at a much earlier age than sixty-five (p. 23).

The literature rarely speaks of the problems of DD persons in general. Usually, the discussion centers on the older retarded client; therefore findings concerning this group of DD persons are used in this study to address the situation of DD persons generally.

This study will follow Thomas's (1978) conservative lead and define thirty-five years as the onset of "aging." The term "aged" will not be defined in terms of specific behavioral or social correlates but rather as a somewhat arbitrary subcategory of the "aging" population, that is, those aging persons sixty-five and over. Aging/aged DD thus refers to t[illegible] persons included within the legal definition of DD who are thirty-five years or older.

ISSUES RELATED TO SERVING THE AADD POPULATION

Scott (1974) notes that service organizations are often more likely to serve clients who are "attractive" in certain ways (e.g., young, able to be rehabilitated, ear-marked for funding). An understanding of the community service support system for AADD clients must begin by seeing just how "popular" they are with human service organizations. As we have seen, the normalization model of human service delivery is intended to be an alternative to the institutionalized destruction and continued discrimination which results from attributing the role of deviant individuals to handicapped individuals. In identifying the number of agencies which serve the AADD population we will attempt to determine whether or not the data suggests a service policy which discriminates against the AADD client group.

It is also especially important to note the total number of AADD clients served by the selected agencies. A recent study done in the Cleveland, Ohio, area (Report to the Congress, 1977), indicated that fully 50% of the services received by older persons at all impairment levels were provided by family and friends, while over 70% of the services provided for extremely impaired older persons were provided by family or friends.

It seems there is a great possibility that AADD clients will remain "invisible" to human service agencies unless special attempts are made to identify these potential clients. By an extrapolation procedure described in the Findings section, it is possible to estimate the number of AADD clients being served in Wisconsin and to compare this figure with the number of AADD persons estimated to be living in Wisconsin.

The oldest AADD clients (sixty-five and over) may be receiving services more frequently than younger AADD clients. This may mean that service organizations are not aware of DD persons until they qualify for programs for senior citizens.

Furthermore, within psychology, especially in community psychology, there is a growing commitment to an active, seeking model of service delivery as opposed to the traditional passive, "serve when called to serve" model. A rough index of the degree to which human service organizations currently employ a passive or active service delivery model can be obtained by examining the number of AADD clients served. Dickerson's (1974) findings suggest that substantial "client find" activities are needed to serve the AADD population. If relatively more AADD persons are being served one would suspect that the selected agencies employ an active service delivery model.

A corollary of the normalization principle is that services should be provided in an individualized fashion, taking into account the relevant characteristics of the client. Individualized services would logically begin with definitive client identification. Hasenfeld (1974) reasons that human service organizations have a responsibility to identify their clients accurately.

> Organizations that delimit their interest in the client's biography force the inherent problem of isolating a specific set of client attributes from the rest of his biography . . . organizations whose interest in the client's biography is extensive are in constant search for relevant and significant attributes (p. 7).

The selected agencies' ability to identify their clients as both aged and DD yields a rough index of their awareness of AADD persons as a unique client group.

The principle of normalization has been used most extensively in residential care facilities. As yet, there is no set pattern of community support services for AADD persons which would constitute a normalizing service system. However, the essential characteristic of this kind of service is that it causes some beneficial change in the client. It can be a physical change, as in the development of a work skill. Examples of services which cause this kind of change are vocational training or sheltered workshops. The beneficial change in the client could also be cognitive. Educational classes, therapy and counseling, or services geared toward the clients' realization of religious values are examples of services which have the potential to cause cognitive change. While "causes change" is admittedly a loose criteria for evaluating services, such an evaluation will be made here bearing in mind the methodological shortcomings of such an analysis.

METHODOLOGY

Research Questions

The issues outlined in the previous section can be reduced to the following five research questions.

A. How many of the surveyed organizations serve the AADD population? Question A will be addressed by examining responses to survey item 1: "Does your agency provide services for older/aged developmentally disabled persons, age thirty-five or over?" and by analyzing the percentages of the total AADD group served by each type of service organization.

B. How many AADD clients are served? Question B will be addressed by noting the number of AADD clients reported in response to survey item 3. "Please list the number of older/aged developmentally disabled clients served by your agency from January 1, 1977 through January 1, 1978 by chronological age."

C. What type of AADD clients are most often and least often served? Question C will be addressed by examining responses from survey item 3, quoted above, and from survey item 4: "Please indicate the number of older/aged developmentally disabled clients served by your agency from January 1, 1977 through January 1, 1978 with each of the following handicapped conditions as primary diagnosis (epilepsy, cerebral palsy, autism, mental retardation, and multiply handicapped)."

D. To what degree are service organizations able to identify AADD clients as aging and/or disabled? Question D will be addressed by examining the numbers of agencies able to respond to survey items 3 and 4, and by analyzing responses to survey item 5: "If you were unable to complete questions 3 and 4 above, please indicate why."

E. What is the emphasis in the services provided to AADD clients? Question E will be addressed by analyzing responses to survey item 6a: "Check which of the following services your agency provides to older/aged developmentally disabled clients" and item 6d "Has your agency identified client needs which are not being met? If so, what are they?"

Sample Population

Data for this study was obtained from responses to a questionnaire entitled "Assessment of Community Services for Older/Aged DD Persons" (See Appendix A). Questionnaires were mailed to 89 Wisconsin service agencies in the Madison and Milwaukee areas. Fifty-five agencies responded to the survey for a 62% response rate. These agencies included public, private, consumer agencies, nursing homes, public schools, and colleges and universities. All of the public, private, and consumer agencies, as well as the public schools and colleges/universities were surveyed. In addition, a systematic sample of one-fifth of the nursing and retirement homes were sampled by selecting every fifth home from the Milwaukee and Madison telephone directories after a random start.

While most of the categories are self-explanatory, private and consumer agencies need some elaboration. Examples of private agencies are Planned Parenthood, Goodwill, Catholic Social Services, and YMCA/YWCA. Consumer agencies included are Associations for Retarded Citizens, senior clubs, United Cerebral Palsy, and Citizens for Better Care.

Statistical Analysis

The nominal nature of the questionnaire severely limited the kinds of statistical analysis which could be performed on the data. Data analysis consisted of descriptive statistics (percentages and frequency distributions) computed directly from responses to questions on the questionnaire. To provide a more indepth view of trends, cross tabulations of key variables were also obtained through analysis of variance and chi square tests as suggested by the descriptive breakdown of the data. Only those tests which were statistically significant at the $p < .05$ level and above are reported here.

The nature of the data also severely limits the generalizability of findings and the interpretations which can be made upon them. Realistically, this study applies only to Wisconsin service agencies, although similar findings for all of HEW Region V are reported in the chapter of this monograph by Sweeney.

FINDINGS

The data presented in this section is organized around the research questions listed above.

A. How many of the surveyed organizations serve the AADD population? Table I indicates the number and percentage of those Wisconsin agencies which responded to the survey which do in fact serve the AADD population.

Table 1

Agencies Serving the AADD Population

	TOT.	PUB.	PRI.	CON.	NUR.	P.S.	C/U
Agencies Responding	55	26	5	2	12	7	3
Agencies Serving AADD	28	17	4	1	4	1	1
% Agencies Serving AADD	50	65	80	50	33	14	33

It is apparent from Table 1 that private agencies (80%), followed by public agencies (65%), are the most likely to serve the AADD population while public schools (14%) are the least likely to serve. It is equally obvious that nearly half of those agencies selected for the survey are not serving the AADD population.

Table 2 indicates the number of AADD clients and the percentage of the total group served by each type of service organization.

Table 2

AADD Clients Served by Agencies

	TOT.	PUB.	PRI.	CON.	NUR.	P.S.	C/U
AADD Clients	1717	1142	51	5	418	81	20
% of Total	100	66	.03	.002	24	.05	.01

Table 2 indicates that public agencies are serving the largest percentage of AADD clients (66%), with nursing homes serving the second largest percentage (24%). Consumer agencies are serving the smallest percentage of AADD clients (.002%).

One cannot attribute the overall lack of service to a discriminatory service policy even though the fact that only 50% of those questioned reported serving AADD persons certainly points in that direction. However, it would be naive to think that no discrimination is involved in client selection practices. Therefore, we can at least speculate about the possibility of such discriminatory practices by examining one particularly striking finding in the data which is that only 33% of nursing homes are serving the AADD population (Table 1). This is even more curious when one considers a later finding that well over half of all the AADD persons noted in the survey are sixty-five years or older! Furthermore, nursing homes serve 24% of the total AADD group in the survey (Table 2). We must at least entertain the possibility that nursing homes are limiting admissions of AADD clients because of the "unattractiveness" of these clients. Such unattractiveness could be in terms of the cost-profit ratio associated with meeting the extra needs of impaired aged persons, or it could be in more literal terms. Wolfensberger (1972) notes that a segregationist philosophy in human services calls for the sparing of normal persons the "discomfort" of associating with deviant individuals. Nursing home admission policies may be designed to spare older persons (themselves deviant but not as deviant) from persons who are old and physically or mentally impaired. As such it would certainly constitute an example of "handicappism," or discrimination against DD persons.

Of course, the fact that 33% of nursing homes are serving AADD persons does not necessarily indicate "handicappism." There are other reasons which can potentially account for such a low rate. One such reason might be lack of staff trained to deal with the AADD client's special needs. Another would be inadequate funding to supply needed equipment.

Psychologists have increasingly turned to an examination of institutions and institutional practices in addition to individual human behavior. The findings concerning the low percentage of nursing homes serving AADD persons, together with the overall low percentage of human service organizations serving AADD clients would seem to raise several future research questions. Primary among these is the question of overt discriminatory client selection criteria. Wolfensberger's (1972) treatise on the power of unconscious ideologies in determining institutional practices suggests an analysis sensitive to instances of covert discrimination as well. For example, are service agencies "selectively attending" to non-AADD persons in outreach or client-find activities, thus not "seeing" or serving AADD clients? Is there congruence between client selection criteria and the organization's stated service goals? How are selection criteria determined, by whom, and how modified? Based on the answers to these and other questions concerning client selection procedures, appropriate intervention strategies could be developed including the "unmasking" of any institutionalized discriminatory practices.

B. How many AADD clients are served? The best available estimate indicates that the total population of the areas surveyed is 1,718,000 (Statistical Abstracts of U.S. 1976). The same source estimates that 41.5%, or 712,970 of this population are thirty-five or older. Using the 4.3% prevalence rate for DD suggested by Hammer and Richman (1975), 30,657 persons aged thirty-five +, residing in the area surveyed, could be expected to have a developmental disability. If all agencies who said they were providing services to AADD persons were providing service at the same rate, and if the percentage of agencies providing service among nonrespondents is assumed to be the same as that of respondents, then the total projected number of AADD persons receiving service in the sample area would be 5,867. If these assumptions are valid, then only 19% of the projected AADD persons in the sample area and in Wisconsin were receiving service. Calculations appear below.

Estimate of Total AADD Persons Served

Number of AADD persons served by non-nursing homes = 1299

Average number of AADD persons served by reporting agencies = 30

Potential AADD persons served by other agencies in survey area (.56 x 68 x 30) = 1,142

Potential AADD persons served by nursing homes = 4,725

Potential AADD persons served if all agencies are assumed to be providing service equally = 5,867

Potential AADD persons 35+ in survey area = 30,657

$\frac{5,867}{30,657}$ = 19% of potentially AADD persons served (probably less as non-duplicated account cannot be assumed)

If 50% of the agencies were serving the AADD population it might have been adequate, indeed impressive, if all potential AADD clients were being served. However, potentially 81% of the clients in the selected agencies catchment area were not being served. While there is certainly the possibility that the 4.3% prevalence rate for DD suggested by Hammer and Richman (1975) is too high, it would appear that substantial numbers of potential clients in Wisconsin were not being served.

C. What types of AADD clients are most often and least often served? Table 3 indicates the numbers of clients reported served within each of the three age ranges. Table 3 also indicates the percentage each age group contributes to the total group reported served. Table 4 indicates the frequency of each type of handicapping condition reported, as well as the percentage each diagnosic category contributes to the total group.

Table 3

AADD Clients Served by Age Bracket

	TOTAL	35-54	55-64	65+
# AADD Clients	1717*	261	206	1170
% of Total	100	15	12	68

*The total figure is higher than the sum of the 3 age cells because one agency reported 80 persons (5% of total) but did not categorize these persons by age.

Table 4

AADD Clients Served by Disability Type

	TOT.	EPI-LEPSY	C.P.	AUTISM	M.R.	MULT. HAND.
# AADD Clients	327*	24	13	1	143	146
% of Total	100	7	4	0	44	45

*The number of clients reported by disability type was significantly fewer than reported by age. This would seem to reflect a general practice among service agencies to keep records by age but not by disability.

It is apparent that within the selected Wisconsin agencies, AADD persons sixty-five and older were very much more likely to receive some kind of service than persons in either of the two other age brackets. Also, mentally retarded and multiply impaired individuals are clearly more prevalent in the service population than were other disabilities.

The data concerning the disproportionate numbers of aged (65+) AADD clients in the service population was particularly striking. There was a gap in the service to clients after adolescence, when schools are primarily responsible, (especially with the passage of the Education for All Handicapped Children Act of 1975) until old age, when clients fall under the aegis of programs for the aged, such as Social Security.

These findings raise several further questions. Are there really substantial numbers of AADD citizens in need of service in the population or are these estimates falacious? One could make the argument that the relative paucity of clients in the 25-64 age range is due to the success of school programs in preparing individuals to lead full and independent lives, and hence they don't need service! Perhaps, too, the substantial numbers of AADD citizens apparently cared for in the family home are doing well without supportive services. We must investigate the ways in which developmentally disabled persons successfully or less successfully cope with their problems in living at various ages. The problems of developmentally disabled citizens throughout the life span and especially upon reaching adulthood are not yet clearly understood. Dickerson (1974) notes that we know very little about AADD persons. In his chapter in this volume, Sweeney notes "The lack of information concerning the AADD population is readily understood when one considers that the general area of aging has only been a topic for research only for the last twenty-five years and the specific area of AADD has only attracted interest over the past five years." To understand why many AADD persons are apparently not receiving services, especially in the prime years of their lives (35-54), we must develop a clearer picture of the reality surrounding their day-to-day existence.

One other implication of the findings has to do with the "style" of service delivery. With so few AADD persons being served it would appear that the selected service agencies are operating out of a passive mode of service delivery as opposed to an active, seeking mode. If this is true, it would seem highly beneficial for human service organizations to begin to seek out AADD clients.

D. To what degree are service organizations able to identify clients as aging and/or disabled? Tables 5 and 6 indicate the percentages of those agencies which were able to respond to questions 3 or 4 on the questionnaire, thus indicating their ability to categorize the AADD population by one or the other of the two primary defining characteristics.

Table 5

Agencies Able to Provide Information by Age

	TOT.	PUB.	PRI.	CON.	NUR.	P.S.	C/U
Yes	50%	35%	50%	100%	100%	0%	100%
No	50%	65%	50%	0%	0%	100%	0%

Table 6

Agencies Able to Provide Information by Disability

	TOT.	PUB.	PRI.	CON.	NUR.	P.S.	C/U
Yes	43%	29%	50%	100%	75%	0%	100%
No	57%	71%	50%	0%	25%	100%	0%

Table 5 indicates that generally 50% of the agencies were able to identify their clients by age, and Table 6 indicates that 57% were able to identify clients by type of disability. Public agencies were generally unable to provide demographic information while nursing homes were often able to provide that information.

It is obvious that there was great variation among the types of agencies as to their ability to provide minimal demographic data (age and disability) about their clients. It is understandable that public schools, which do not usually serve the age range included in this survey, would not be able to provide this data. However, it is rather striking that public agencies which serve the vast majority of AADD clients, were the least able to provide demographic data.

How appropriate can the services provided be if all that a person is, is not considered? For great numbers of AADD clients, there is a high probability that services were not being provided with sensitivity to the unique problems that age and impairment fostered upon them. A broad conception of the client's minimal competencies and maximal potential is not built in to service programming.

What reasons were given by agencies for inability to classify by age or disability? An analysis of the variance in responses to the reason "records not maintained by those categories" found that a statistically significant amount of variability in responses could be accounted for by the type of agency responding. Public agencies were far more likely to indicate that they did not maintain records by age and disability categories. Reasons given for lack of categorization are shown in Table 7.

Table 7

Reasons for Inability to Describe by Age and/or Disability

	PUBLIC	PRIVATE
No records by categories	9	1
No records in this office	1	0
Categories not applicable	1	1
Other	2	0

If we can assume that AADD clients do have special needs and there is a need for more definitive client identification, where shall the effort be targeted? There is a great potential for "humanizing" service programming by simply designing record keeping systems which do in fact describe AADD persons as unique clients. This would certainly seem to be the kind of organizational or systems intervention which psychological practitioners interested in human welfare institutions should attempt. The result would be a system of human classification which service planners could use to build a service plan with client development as its primary goal.

E. What is the emphasis, client change or client maintenance, in the services provided to AADD clients? Table 8a indicates the services most and least frequently offered to the AADD population. Table 8b indicates the same information by type of agency for public, private, and nursing agencies. Only one agency of the other types of agencies responded to this question.

Table 8a

Frequency of Offered Services

Most Frequently Offered Services		Least Frequently Offered Services	
SERVICE	% OF AGENCIES OFFERING	SERVICE	% OF AGENCIES OFFERING
Information/referral	73%	Other residential care	25%
Ongoing counseling/treatment	54%	Sheltered employment	20%
Adult activities/recreation	50%	Foster care	17%
Transportation	50%	Vocational classes	13%
Diagnostic assessments	46%	Legal Services	8%
Personal advocacy	46%		
Income maintenance	46%		

Table 8b

Most Frequently Offered Services by Agency

PUBLIC		PRIVATE		NURSING	
Info./Refer.	93%	Info./Refer.	67%	Medical Treat.	100%
Ongoing Couns./Treat.	64%	Ongoing Couns./Treat.	67%	Adult Activities/Recreation	75%
Income Maint.	64%	Diagnos. Assess.	67%	Personal Advoc.	75%
Diagnos. Assess.	50%	Adult Activities/Recreation	67%	Transportation	75%
Transportation	50%	Medical Treat.	67%	Guardianship	75%
		Staff Develop.	67%	Staff Develop.	75%
		Dental Treatment	67%		
		Personal Advoc.	67%		

Least Frequently Offered Services by Agency

PUBLIC		PRIVATE		NURSING	
Educa. Classes	29%	In-home Services	0%	Legal Services	0%
Shelt. Employ.	29%	Legal Services	0%	Foster Care	0%
Medical Treat.	29%	Foster Care	0%	Voca. Classes	0%
Foster Care	29%	Other Residential Care	0%	Shelt. Employ.	0%
Staff Develop.	21%			Other Services	0%
Dental Treat.	21%	Income Maint.	0%		
Voca. Classes	14%				
Legal Services	14%				

From Tables 8a and 8b it is apparent that Information/referral, ongoing counseling/treatment, adult activities and transportation were the most frequently offered services. Other residential care, sheltered employment, and foster care were the least frequently offered services. Nursing homes all offered medical services.

It is quite difficult to translate the normalization principle directly into evaluative criteria for judging services provided by both residential and non-residential facilities. However, the data suggests that services were not generally being aimed at client change and development and were aimed at client maintenance.

If we look at the most frequently offered services (Table 8a), one service, "Ongoing Counseling/Treatment," had the potential to change the AADD client positively. And even this service was offered only 50% of the time (although public agencies, which served the majority of the AADD clients, did offer this service 64% of the time). Nursing homes, which had the second highest number of AADD clients, did not provide this service as frequently as other services. Now, the point should be made that all nursing homes did provide medical services which can be considered to cause positive change in clients. However, within the normalization perspective, we are more concerned with change which leads toward cognitive or spiritual development or the development of work skills to aid independent living. Consequently, medical treatment would not be considered truly normalizing. Nursing homes emphasized client maintenance.

Personal advocacy should be included as a normalizing service. Private agencies and nursing homes (and, one suspects consumer agencies as well although too few responded to suggest any trends) are actively engaged in personal advocacy for AADD clients. We simply cannot determine the nature of the advocacy provided from the data.

Overall, the most frequently provided services would not cause positive change in AADD clients. Information/referral, adult activities/recreation, transportation and income maintenance cannot be said to aid in the development of work skills or the actualization of cognitive or spiritual potentials (Segal, 1977). Diagnostic assessment may provide a baseline for individualized, normalized service planning (in much the same way as accurate record keeping might). However, in and of itself it cannot be considered to facilitate positive change.

Generally the services which cause positive change were among the least offered services. This trend was most clearly seen in the list of least frequently offered services for public agencies. Educational classes, sheltered employment, and vocational classes were all offered infrequently.

No services geared toward client development, again with the possible exception of advocacy, were mentioned as unmet service needs of AADD clients. Fifteen or 54% of the serving agencies indicated that they recognized client needs which were not being met. However only three such needs were specified: transportation, outreach services, and housing.

The picture remains cloudy. However, the findings do tend to suggest that services provided by the selected agencies were not geared toward normalizing AADD clients. A need exists for the development of more growth oriented services. The services provided which did emphasize development should be offered more frequently.

Services must be predicated on an understanding of AADD client needs and "meta" needs. One suspects there is a real need for services which would help the AADD client to deal with sexuality, with interpersonal issues, with money management, and with his own sense of differentness. We must also investigate what staff training and education is needed to implement a developmental service model. Undoubtedly the traditional barriers between staff and clients which serve to isolate deviant individuals from normalizing human contact must be lessened. At present this knowledge is unavailable. Psychologists and other social scientists could serve the AADD population by attending to these issues.

DISCUSSION

Summary

The major findings concerning community services for AADD persons in Wisconsin are summarized below.

First, overall, only 50% of the agencies surveyed served AADD persons. Private agencies were the most likely to serve AADD persons

(80%), followed by public agencies (65%).

Second, a total of 1717 AADD persons were reported served by the selected agencies. This figure was used to estimate the percentage of AADD persons currently in Wisconsin. Only 19% of the total Wisconsin AADD population was receiving services.

Third, public agencies served the most AADD clients (66% of the sample), followed by nursing homes (24% of the sample). Consumer organizations served the fewest (.002% of the sample).

Fourth, 68% of the total sample were identified as 65 years or over, 13% were identified as 35-54, and 12% were identified as 55-64.

Fifth, 45% of the total sample were identified as multilpy handicapped, 44% were identified as mentally handicapped, and 11% of the total were identified as having other primary diagnoses.

Sixth, generally, agencies were able to provide the age of their AADD clients 50% of the time. They were able to identify the primary handicapping condition 43% of the time.

Seventh, the most frequently offered services were information/referral, ongoing counseling/treatment and adult activities/recreation. The least frequently offered services were other residential care, sheltered employment and foster care.

Eighth, unmet client needs were identified by 54% of the selected agencies. These included housing, advocacy, and outreach services.

Ninth, the source of agency funding (e.g. federal, state, county) made no substantial difference in the services provided to AADD clients. 64% of the selected agencies received federal funds, 54% received state funds, 28% received private funds.

Tenth, the most frequently observed obstacles to service delivery were a.) inadequate funds, b.) transportation, c.) lack of community support services, d.) difficulty of maintaining staff, e.) attitude of community towards clients.

Eleventh, when asked what additional services the agency would provide if funds and staff were available, only 16 agencies responded. Paradoxically, the most frequent response was "no additional services."

Towards a Social Policy for AADD Persons

In the last two decades there has been an increase in concern for the plight of individuals who are in some way physically or mentally impaired. There has been a concurrent social awakening to the problems faced by older citizens. For example, in 1965 the United States Congress passed the Older Americans Act. Ten years later the Developmentally Disabled Assistance and Bill of Rights Act and the Education for All Handicapped Children Act were passed. However, Thomas (1978) raises a critical issue with regard to those persons who are at the intersection of the DD and older populations, the aging/aged developmentally disabled.

> Because aging and aged people are not identified as a group, they do not have the power to advocate for themselves. They are not seen as part of the increasingly vocal non-disabled elderly population. Nor do they have a visible place in the planning for DD citizens. (p. 3)

It is clearly evident that services are not being specifically targeted towards AADD clients. At issue is the responsibility of lawmakers to adequately provide for the well being of all citizens.

Cohen (1978) notes that the criteria used to categorize individual in social policy formulation are often arbitrary. For example, the decision to use 65 years of age as a starting point for Social Security benefits was an arbitrary decision. No wealth of empirical research was used in making that decision. Law makers in 1936 simply felt 60 was too young and 70 too old! However, a curious consequence of such arbitrary decisions is that they come to delimit social values. Hence we now think of old age as "beginning" at age 65, as if some real physical or mental change occurs upon reaching that age.

With regard to AADD persons, the decision to target funds and social programs on the basis of age or disability may have been an arbitrary "common sense" decision. However, the result is that AADD citizens are not being provided for in a manner commensurate with their need. Key areas in which current social policy is not adequately providing for AADD citizens are outlined below.

One key issue is health care services. AADD persons are covered under the Medicare and Medicaid provisions of the Social Security Act. These programs were designed and continue to be administered for the elderly population in general, with no special provisions for handicapped elderly. Cohen (1978) has suggested that medical costs are generally three times greater for persons 65+ and the medical costs of older disabled persons may be as much as 25% greater than for non-disabled persons. Not only is there a possibility that special needs are not covered within the established health programs, but recent Social Security Amendments (1972) which call for reclassification of patients to lower levels of care (e.g., from nursing homes to less well equipped homes) may be resulting in patient transfers which do not suit the special needs of AADD clients.

In the area of employment, there are a variety of work programs for the elderly, such as the Older Americans Community Employment Service, Service Corp of Retired Executives, Retired Seniors Volunteer Program, and Volunteers in Service to American (VISTA). However with the exception of VISTA, none of these programs give any special consideration to the physically or mentally impaired. Consequently, AADD citizens remain out of the labor force and are often totally dependent on Social Security payments for income.

Psychologists can have an important impact on social policy for AADD citizens. One important activity which could eventually lead to a social policy for AADD citizens is to document their existence and their special problems. Large numbers of AADD citizens are not being served by human service organizations and the services which are rendered are not provided with an awareness of the AADD citizen as a unique client with unique characteristics. Before any legislative body will act on any group's behalf, they must be made aware of the problem(s) and must know that there is a large or at least vocal constituency clamoring for reform. In the case of AADD citizens, we have seen that so little is known about their life circumstances that we cannot even be sure what services are most needed. It is doubtful that any legislative remedy will occur unless the problems and needs of the AADD citizen are articulated.

Proposals for change must include solutions, and psychologists must demonstrate through empirical research that the programs and services they recommend will work. For example, if we call for more vocational classes and sheltered workshops, we must be able to demonstrate that these activities will have tangible benefits such as increased self esteem, supplemental income to the AADD citizen, and increased potential for a normal pattern of existence through participation in the labor force.

Finally, psychologists can act as advocates for AADD citizens, who, as a group, are unable to articulate their plight. This means going to Congress or state legislatures and speaking at the hearings which could have an effect on their lives. The Social Security Act is currently under debate--psychologists interested in helping the AADD citizen should be presenting their story in those discussions. Furthermore, pressure for legislation often comes from an aroused public. Psychologists must also be willing to "hit the road" and educate the lay public in any and every forum available.

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TEACHING AND LEARNING: THE EDUCATIONAL ROLE OF THE UAF AND IMPLICATIONS FOR SERVING THE AADD CLIENT

Eunice Thurman

PREFACE

By assessing community services available throughout Region V, the main body of this research monograph[1] describes services available to AADD clients, problems of client identification, impediments to service delivery of this age group, and implications for inservice training in light of the survey results. This chapter of the research monograph discusses the UAF and its role in the service delivery to AADD clients.

The project collected, organized, and analyzed data to provide an information base for planners and decision-makers at all levels of the delivery system. The project also surveyed all UAF's and other selected institutions and agencies nationwide charged with training individuals and providing service examples to DD populations at all levels of the delivery system. The results of this latter survey are analyzed here.

INTRODUCTION

Although there are well recognized deficiencies in this survey design, the results of the study still point to the strong possibility of a lack of service and education to the AADD client. The readers of this article would do well to consider the questions that this study raises, and attempt to clarify them by further research.

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[1] This project of National Significance was funded by HEW through P.L. 94-103. It is a three-year grant awarded in 1976, to ISMRRD, which is one organization of a nationwide network of designated University Affiliated Facilities (UAFs). The project is entitled, "Serving Aging and Aged Developmentally Disabled Persons." In this research paper, AADD will be the acronym for this designated group.

The UAF mandate mainly includes an educational and training role, as well as provision for the establishment of model programs and service implementation. Because of its leadership role in these areas, the UAF is one of the most relevant organizations to analyze in terms of the provision of services to the AADD clientele. If the AADD client is truly "invisible" (Dickerson, 1974), UAFs must share the responsibility for decreasing this invisibility. The findings seem to bear out a rather pessimistic picture. The UAF does not appear to be providing service or leadership in terms of research, effective programming or ultimately meeting the individual needs of each AADD client.

The apparent significance of the findings in this section of the research paper will have far reaching implications beyond the UAF itself, and will strike at the very heart of the issue. In other words, if service is not being provided at the agency and UAF levels, then is service being provided? And most importantly, if the UAF is not providing the education and research component in the area [illegible] AADD, then who is providing leadership?

The problem, therefore, extends beyond provision of service. It seeks to approach the issue in terms of how an organization as influential as the UAF, can use its powerful position to initiate changes in its own organization and in general social policy concerning the AADD. It is the UAF that should be the first to ask itself whether it is being sensitive to the new and changing needs of the AADD client. Its example can provide influence and direction in an area that is fast becoming a major issue.

The UAF must change or become an anachronism and risk the possibility of funding loss, under the provisions of P.L. 94-103 and section 504, as well as Title IX.

ISSUES

In the following discussion, various topics which are linked to the issue surrounding the AADD are presented. The relevance of these issues to the UAF and its position as concerns the AADD client will be clarified in the main body of this chapter. From this discussion one can formulate some hypotheses which will be focal points in considering the survey that was conducted.

History of Legislation Related to AADD Persons

Concern for developmentally disabled persons has increased over the last fifteen years, its initial impetus being the President's Council on Mental Retardation in 1963 (Browning and Brummer, 1972). Many legislative changes have taken place since then: P.L. 91-517 - the Developmental Disabilities Services and Facilities Construction Act of 1972; Sec. 504 of P.L. 93-112 as amended by P.L. 93-516 - the Rehabilitation Act of 1973; P.L. 94-103 - the Developmental Disabilities Assistance and Bill of Rights Act of 1975; and P.L. 94-142 - the Education of All Handicapped Children Act of 1975 14th Amendment of U.S. Constitution - Equal Protection and Due Process (Hammer & Richmond, 1977b).

These changes in policy toward the DD population have resulted in concern for an age group of DD persons who have previously been termed "invisible" (Dickerson, 1974), namely the aged and aging developmentally disabled. First of all, this concern has naturally evolved because concern for meeting individual needs of DD persons has resulted in mandated legislation to that effect (Hammer & Richmond, 1977a). "As is true of the ecology of all human conditions, attention paid to some problems serves to rai[illegible] others previously unforseen. It is the task of those concerned with mental retardation to consolidate the gains made during the 1960's and to expand those gains toward the ultimate goal of serving more persons comprehensively" (Browning and Brummer, 1972). In the DD Law of 1975, the most recent attempt to provide comprehensive services to the DD population has been formulated. In it, all DD persons are to be given appropriate treatment, services, and habilitation. Also, it mandated the delivery of services so that the developmental potential of each person is maximized and that there is access to the least restrictive environment. Other characteristics of DD services mandated by the DD Act include: emphasis on coordinated, life-long support services for the DD person and his family, a state plan for the provision of service, and DD councils that must be sensitive to the issues of all DD persons and submit the State Plan (Browning and Brummer, 1972);

The timeliness of this entire research project is evident here. It is quite clear that meeting the needs of the AADD client is a required part of all service providers' programs.

Social Forces that Precipitate Concern for the AADD

Various social forces have led to these new laws. The concept of normalization is one of them. The principle of normalization was developed in the Scandinavian countries, and it refers to the normal development of the DD individual and his family in regard to the use of services in the community. It also included the development of the normal community in relation to care and management of normal living activities for DD persons (Andrews, 1972).

The concept of normalization has been criticized for a number or reasons. Mesibov (1976) has studied the concept and states that certain concepts concerning it are not verifiable. That it improves public attitude has not been proven; it is not clear what is "normal"; it deals with service systems instead of individuals, and because of this individual needs can be misdirected and misinterpreted; retarded people do need extra help. Throne (1975) affirms this latter point when he says, "While specialized procedures may or may not succeed in helping the retarded to become more normal, they always are the prescription of choice over normative procedures if more normal lives for the retarded are indeed the ends sought" (p. 23). An inherent danger in normalization, then, is the ease with which one is able to do nothing, or in doing something, is more likely to be doing it to maintain the system (agency, UAF) than to meet the individual needs of the client, including the AADD client.

The Importance of the Developmental Model

From this discussion on the concept of normalization, the influence of the developmental model can be seen. The key is meeting the needs of each individual; it implies that everyone has growth and capacity to learn--regardless of age or handicap. "Although particularly appropriate for children, the developmental model is equally meaningful when applied to adults." (Wolfensberger, 1969a, p.82)

This model has particular relevance to the aging DD in regard to services. Developmental disabilities are by definition life-long; yet arbitrary service limits are set. As soon as adulthood is reached, the maximum benefits one can receive from the support system have been attained, and services are terminated (Dickerson, 1974). However, research bears out the fact that these services are desperately needed all through adulthood (Gordon, 1977).

Some Issues Surrounding Normal Aging

Moving, then, from the idea of the developmentally disabled person as learning and growing, one can now consider the implications of this for the aging person, both normal and disabled. If the needs of the normal older citizen in our country and the impediments which exist in satisfying these needs are first considered, one can gain valuable insights.

Aging cannot be considered by chronological considerations only, but its different dimensions must be considered in light of their effect on each individual. These different dimensions include the social, psychological, and biological (Neugarten 1968, Goldman & Rockstein, 1975).

Sociologically, we find the elderly person in what could be termed a "changing age-status system" (Neugarten, 1968). During his lifetime the person moves through various social events which determine his role as a child, adolescent, or adult. Along with these events go certain privileges, and they are directly related to one's social status. Examples of these life events include marriage, having children, employment, voting, and retiring.

When the concepts of social age and age status are considered, economic productivity is often regarded to be the age when "maturity" is reached. When a person retires, there are certain social consequences. In our industrial society, to be productive is to be useful. Therefore, the delineation of a special age group based on economic productivity has tended to lower the status of the aged. Along with sharp differentiations in age groups which are characteristic of a highly technical society, we find older people regarded as old and useless (Neugarten, 1968).

Aging and DD

The issue here is a group's right to exist outside of their usefulness to society. This is the problem DD people often face their whole lives, one that hits the normal population at retirement age. Because society will become more technological, the minimum intellectual demands on both the retarded and normal population will spiral upward as the number of unskilled jobs decreases. But it will not only be the DD who suffer. "A growing proportion of the society may be faced with the same emotional and personal adjustment problems that face the retarded individual now" (D'Alton, 1970). It is because of this very point that the industrial society as it moves into the post-industrial era must face the fact that we can no longer equate the value of any human life with productive capacity. Kriger (1975) believes that because the aging retardate has not participated in the formal educational process, or in gainful employment, in the process of aging his personal views on aging will be quite disparate from those of a normal aging person.

Researchers in aging have suggested a number of ways in which older people cope with pressures. Cumming and Henry (1961) have developed the theory of disengagement; Havighurst and Albrecht (1953) have developed the theory of activity. Both of these theories explain the ways in which a person reacts to growing older in terms of maintenance of life satisfaction. Dowd (1975) feels that neither the disengagement nor the activity theories explain what happens. He feels that problems of aging have to do with decreasing power resources. Older people don't have as much of value to exchange because value is placed on economic productivity. Therefore, the aged must offer compliance so that they can continue to subsist.

Even though there are questions as to whether adjustment of DD persons to their aging is similar to the normal population it is hard to deny that they experience many of the penalties that old age brings to the normal aging population. According to the exchange theory mentioned previously (Dowd, 1975), the older person is exchanging compliance for continued sustenance. For the normal aging person, power that was once evident by participation in the labor force is now gone. For the retarded, there might have never been participation. Kriger (1975) states that aging retardates often express a high level of satisfaction in whatever situation they find themselves. She expressed concern about this because the retarded person seemed to respond in a positive way to whatever was asked, possibly to "please" the interviewer. If the exchange theory has credibility, the aging DD person in our society has learned that he does not have much to exchange but compliance!

According to the disengagement theory (Havighurst & Albrecht, 1953), many of the AADD have been "disengaged" from the activities of society for most of their lives. According to the activity theory, their lack of involvement in the processes of "normal' community life makes them age sooner, or else it insulates them from some of the psychological problems of the aging population. (If you have never had a well, it's hard to get upset when it goes dry.) Thomas and Acker (1977) make an interesting observation concerning the activity theory and its application to DD populations. They state that the provison of programs to all DD persons is expected no matter how disabled the person is, and without consideration as to whether such programming is effective! "Professionals in both gerontology and DD are increasingly looking at their subjective, often presumptuous, expectations of client behavior" (pg. 12).

The same authors also cite Sidney Kaplan who has compared the roles of the retarded with the aging person. Because of inadequate communication skills, the retarded are often isolated from the mainstream of activity. Kaplan argues that "How we judge the retardate largely determines how we will relate to him and this can in turn influence the speed at which he ages. We have within our power to age these retardates at a greater pace" (pg. 12). Both the normal aged and the aging DD person learn to act in a role that is expected. These roles and expectancies could be altered in both the normal aged and the aging DD.

Once again the issue of individual evaluation and programming comes to the fore. No general statements about a group can be made when providing service. Both service and education must constantly focus on individual client needs.

In an article dealing with loss, Segal (1977) notes that the DD person often experiences loss much earlier in the life span than does the normal person. The DD individual may lose his role in the family prematurely through placement in an institution. Because the AADD often must rely on a caregiver (Kriger, 1975) who is often an aging parent, the loss of this person can be especially profound.

Similarities between the normal aging person and the AADD person have also been noted in areas of money, control, the difficulties in developing self esteem and self actualization due to an inferior social role, and infantilization (Thomas & Acker, 1977).

The demographic considerations are important in understanding the changes in population of both normal aging and aged and AADD persons. Over the years, the control of disease has been quite successful, and therefore older people live longer. Many people would not have lived to reach the older age groups had it not been for the conquest of certain diseases. Not only will lower mortality curves contribute to a greater proportion of the population in the older age categories, but the post-war baby boom which occurred between 1945 and 1957 will also contribute to the phenomenon (Siegel, 1976).

Differential aging represents a progressive decline of vigor and resistance to disease with the passage of time (Goldman & Rockstein, 1975). Regardless of how the DD mortality rates compare with the "normal" rate, the chances of a greater absolute number of DD people living to older ages seem quite clear.

If the changes with age that the normal older person has to cope with are applied to the AADD persons, there is potential for more severe problems associated with these changes. Changes the older person must adjust to include: retirement, a limited income, moving out of one's home to alternate care facilities, living with chronic and worsening physical limitations, and transportation difficulties (Stedman, 1972). Therefore, the need for a differential array of services to meet these problems for both normal aging and AADD populations, and for adherence to the idea that these services must continue throughout life (continuum of service), is essential.

The needs of the AADD client, then, are the same in some respects and different in some respects from those of normal aging and aged persons. It becomes quite clear that emphasis on individual client needs can provide the difference in service delivery between effectiveness and mediocrity.

Quality of Life

When one considers the support system for the AADD client, one finds that many alternative methods of meeting their needs have been discussed and/or implemented. The trends in the last fifteen years have been toward normalization, individualization, mainstreaming, community placement, and the establishment of functional criteria instead of categorical labels as a basis for determining service needs. Because of these trends, the view that institutional care is the only alternative to home care has gradually been phased out. But, as Santayana once said, "If we don't learn from history we are doomed to repeat it." The history of the DD person is often tied up with the institution. If one looks at what has been learned in institutions, then possibly more wise and knowledgeable decisions can be made concerning the meeting of needs of the AADD client.

It is the heritage of the institution that is still being fought off today as the battle continues in terms of community acceptance as well as internal institution betterment. Not that all institutions provide inferior care, but there is the possibility of inferior care being given unintentionally. Psychologically, culturally, and educationally deprived care should not be allowed to exist in any setting (Dinnage, 1960).

Few studies document the widely assumed negative impact of the institution on the individual DD person of any age, and yet it is important to deal with this issue to determine effective social policy for the AADD. As was mentioned, there is the movement today toward small, residential community settings. Yet, little empirical research has been done to document any advantages it might have. "If policy-makers cannot demonstrate that regional centers or group homes are cost-effective, it would be difficult to resist such arguments for central institutions" (Zigler & Balla, 1977, pg. 2).

From the sparse studies that have been done it seems that *type* rather than *size* of the institution is significant. King (1971) words this in terms of resident-oriented vs. institution-oriented care. Designing units small enough to force one to see the DD person as an individual seems important (Zigler & Balla, 1977).

Sara Kriger's (1975) study of the aged retarded in Ohio living in community settings has some interesting implications for AADD persons in general. Although movement to community placement has been the trend, the elderly retarded have not yet been truly involved in community activities. Most of their activity has revolved around their residence and the life of their caretaker. Kriger also found that it was not the physical living arrangement that was important to the person's quality of life, but the adequacy or inadequacy of the environment to meet the physical, social, and emotional needs of the person.

It is not institutional placement or community placement per se which determines quality of life, but the meeting of individual needs. These individual needs must be met by various support systems if quality of life is to be maintained for AADD persons.

Implications for Defining the Populations

It is important to remember that inadequacies that exist in meeting the needs of all DD persons are integrally related to meeting the needs of the AADD subpopulation. It is equally as important to remember that, as mentioned earlier, there are similarities and differences in the needs of the normal aged population and the AADD. Therefore it is important to define the AADD population and the normal aged population.

However, needs cannot be met by providing categorical services to labeled groups. This is only the "band-aid" approach and is extremely ineffective. If individual needs of all DD people are to be met, then one must draw on the services and legislation that can potentially benefit an individual AADD person. As Jack McCallister mentioned in 1975 at the "Consultation-Conference on the Gerontological Aspects of MR":

> I don't see the problem of the aging MR as a sweeping separately identifiable social issue. There are good pieces of legislation which have been enacted in aging, transportation, disabilities, and now Title XX in social services. Those federal, legal entitlements can be orchestrated and programmed to meet the needs of the elderly retarded person without identifying a special population and coming up with a whole new cause. This tends to fragment the efforts in Congress and certain of the administrative agencies (p. 133).

There are well supported reasons for including both younger and older DD groups, and separate facilities and services for these groups may not be necessary. However, a reliable data base containing information concerning the numbers and types of AADD individuals is needed (Gordon, 1977; Burr, 1975). Furthermore, Burr also believes that such a data bank should include the range and scope of service provided, geographic factors, and the sources of funding already available. Presently, because of the lack of demographic information on specific clients, the scope of services needed is not well understood.

The Support System-Service Coordination

Because services must speak to the optimal development of the AADD client, the problem of service coordination becomes an issue. Service needs vary according to such factors as age, home circumstances, level of retardation, existence of other disabilities, personal behavior, and employment potential (Andrews, 1972). The issue of multiple handicaps also complicates the picture. The DD person is often handicapped with more than one impairment (MR plus epilepsy or CP). It is often multiple handicaps that exclude the DD person from needed services (Gordon, 1977; Kobrynski, 1975; Dickerson, 1974). As a person ages there is an increase in the number of impairments and in their chronicity.

The AADD person, therefore, does not form a homogeneous group. He could have diversified problems that increase with age. Hence, again the AADD clientele needs long-term, lifelong services of varying types. Gordon (1977) hypothesized that the long-term services provided for the young adult (16-25) would be more numerous over their lifetime than for those currently over twenty-five because of the greater availability of services and advances in technology over the last twenty-five years. He found out, however, that the service needs for both groups were equally as severe. Discontinuity in the services provided for older DD persons seems to be the situation at the present time (Gordon, 1977; Dickerson, 1974; Dybwad, 1970; Rydell, 1972; Tarjan, 1973). "Thus, even if rationales were strong, even if social policies were clearly defined and understood, and even if services were amply financed, the client might still not receive adequate or optimal services because of the fragmented nature of our current service structure" (Wolfensberger, 1969b, p. 370).

The Support System-Research

The other roles that the support system for the AADD must play are not direct service roles, but are still integrally important to the effectiveness of service delivery. Such indirect service roles include: research, funding, and education. It is in these roles that the U.A.F.

has considerable leverage.

Wolfensberger (1969b) speaks to the fact that in all areas of social service, research is at most mediocre.

> Some human management practices that have been employed for decades and that have cost hundreds of millions of dollars, and untold other resources, lack either empirical validation or comparative cost accounting, or both (p. 380).

The research done in terms of the AADD client is meagre, and yet many service have been developed with little or no research (Katz, 1968). As mentioned before, the concept of community placement and the expectations that were carried along with it were never adequately researched.

Research is also needed to evaluate the effectiveness of AADD service programs, characteristics of the population, appropriate training methods needed at all levels, and the knowledge, experience, and skills needed by different disciplines to deal with AADD persons (Allen and Cortazzo, 1970). Such research will enhance the planning, organization, and administration of services to this population. Zigler and Balla (1977) also emphasize the importance of research in the area of quality of life. Very little is known about the present way of life of those who have left the institution in terms of their adjustment. As Tarjan (1973) and Katz (1968) mention, it is hard to reach intelligent decisions or develop sound social policy when there is so little data available. Even when research has been done, there is the problem of dissemination.

> It is unfortunate that much research of direct relevance to services for retarded adults and their families does not reach practitioners in the field setting who could make use of the results to excellent advantage (Katz, 1968).

The Support System - Funding

In terms of funding, all levels--federal, state, and local--are providing funds, and they can be "multiple and sometimes overlapping and competing" (Gordon, 1977, pg. 15). Funds that are not directly labeled for use by DD populations could be utilized, but because there is no coordinated planning, there oftentimes is no application made for funding. This suggests the need to clarify and streamline existing funding mechanisms if the maximum benefits are to be derived from allocation for DD services (Gordon, 1977). In terms of federal program resources, SSI funds are paid to 1.5 million eligible adults; many more could be enrolled. Through Title XX of tthe Social Security Act there are new advantages available to the disabled. However, states currently match only 1.7 billion of the available 2.5 billion annually. DD councils can make significant contributions to state and local manpower training and can influence funds to programs that benefit the DD. The Housing and Urban Development money available through the 1974 Community Development Act awards [illegible] billion annually; it contains specific guidelines for the protection of the handicapped and elderly. "These statutory safeguards will only be enforced when DD advocacy groups, such as DD councils, become actively involved in the state and local community development planning process." (Hammer & Richmond, 1977a)

The Support System - Education

The role of education in relation to the AADD client is a broad and pervasive one. When specific areas of educational need are defined, five levels of educational service provision come to the fore: professional, paraprofessional, community, family, and client.

Most colleges and universities do not train in any areas of DD, although the needs in this area are quite clear (Leland & Smith, 1974).

To deal with this, University Affiliated Facilities (UAFs) were established with the partial objective of training students who wish professional training in MR as they continue their regular college program. Their other roles include dealing with all areas of DD in terms of problem-solving, service development and consultation, and integration of university and community agency programs (Leland & Smith, 1974). They have complete professional libraries, interdisciplinary staff meetings, and staff attendance at professional conferences (state, regional, and national). All of these aspects of education relate to whether there is a maintenance of sensitivity to all present and emerging need areas in regard to the AADD (Leland & Smith, 1974).

Because staff shortages are quite evident in all service areas, training must also be provided on the paraprofessional level. It is at this level that direct client contact is most frequently made, and therefore the development of adequate skills is imperative and critical. For example, in the selection and preparation of foster care parents, there must be a sensitive assessment of the foster parents' ability not only to accept and understand handicap but simultaneously to develop management skills. A study of the normative behavior of MR adults who successfully adapted to community placement found that care staff needed to be concerned but also needed to be informed (Katz, 1968). "The results suggest that programs for caretakers on skill acquisition and behavior modification should become a vital ingredient to community placement programs" (Nihira & Nihira, 1975, pg. 13). The implication for training paraprofessionals in the area of the AAD subpopulation is clear.

Community public awareness programs should improve community understanding of the problems of the DD person. Such programs would help in the integration of the AADD person in the community, and also add to the ranks of those who would advocate for the group (Katz, 1968).

Families must also be trained to meet the needs of their AADD members. They are often the primary caretakers, and therefore their training needs are similar to the paraprofessional's. Special training concerns here are important as well. The family member who is a primary caretaker is himself/herself growing old and should be informed as to how to cope with this in relation to the DD person.

Finally, AADD persons themselves must be trained in all areas that relate to their capabilities and the development of their maximum potential. Such education programs could be initiated by the agency or the community itself. They could include all relevant academic topics, practical and recreational arts, basic living and coping skills, and vocational skills (Katz, 1968).

The UAF - Its Funding Mandates

In light of the social and political evolvement of the DD person and the aging person concerning rights to service, and of the older DD client as part of this group, one can analyze the role of the U.A.F. in supplying services to AADD clients. All the issues raised in the previous discussion can now be applied to the U.A.F. to help determine where it is and where it must go. After the 1962 President's Panel on MR, the "MR Facilities and Community Mental Health Centers Construction Act of 1963" was signed into law. It provided for the training of professionals in model practice settings which guarantee a continuum of services. They are also mandated to cooperate and coordinate between universities and states to identify and meet manpower needs. In succeeding legislation, including the DD Act of 1972, the UAF received additional authority. This legislation supplied grants to public and non-profit institutions of higher learning to train interdisciplinary, specialized, and generic personnel; to support planning for the construction of facilities which provide a continuum of service to the DD; to supply interdisciplinary training for diagnosis, treatment, education, training, habilitation, and care of the DD persons (UAFs - DHEW, 1972).

The UAF was originally a construction program. Congress then amended it in 1965 under Title V of the Maternal and Child Health and Crippled Children's Services, which later became the Maternal and Child Health Service under sec. 511 of the Social Security Act. It supports the training of professional personnel in the health and service operations for the children at UAF's, and is an important source of funding (UAFs - DHEW, 1972).

DDO funds and BEH funds are also important sources of funding, and together with the M&CH funds supply the majority of monies to the UAF. Maternal and Child Health funds are priority for training professionals to serve the child through age eighteen for medical or health related needs. M&CH money is not to be used for special education purposes. M&CH funding is used to train graduate level preservice students to meet the needs of the pediatric age MR and multiply-handicapped child and his family. M&CH funds do not preclude service to the DD person over eighteen, but they do set a priority as to fund allocation.

BEH funds (Bureau of Educational for the Handicapped) are used for the school age child. Because of the recent legislation concerning mandatory special education (P.L. 94-142) this age extends in certain states to twenty-four or twenty-five. It is considered special education funding, but it is used for educating other disciplines in regard to what they can do to enhance special education services. It is not used to train special education teachers and UAF's, because BEH does that directly through colleges and universities.*

DDO funds are used for overall administration and technical support. They are to be used to meet the needs of DD clients across the life span, and to provide inservice and community service programs to those working with all ages of DD people. Funds are also available through the Office of Education, Rehabilitation Services Administration, under its programs in vocational rehabilitation and the Department of Labor. Also, state, local, university, and other private and public funds have resulted in UAF's with varying interests and objectives (UAFs - DHEW, 1972). Through Projects of National Significance, a U.A.F. can gain funding to do research in areas not ordinarily covered by ongoing funds. Of course, it is important to remember that such funding is short term and cannot be relied upon to sustain an ongoing program. P.L. 9[illegible]-517 extended the grants to include other developmental disabilities besides mental retardation. Staff and service can be added through the medium of support to administration and operation of UAF's. "Thus University affiliated Centers with commitments to activities in the field of MR may continue to maintain that focus in those activities; but grants made under P.L. 91-517 entail the added responsibility of contributing to local, state, regional, and national efforts to meet the needs of the DD of all ages." (UAFs - DHEW, 1972, p. 2)

The UAF - Its Role

The goals of the UAF include:

1. Training of personnel in the administrative, technical, direct care areas, and in other areas needed to maintain adequate provision of service to all DD.

2. Those responsible for training programs must use the available university and regional resources to develop new approaches to interdisciplinary training in MR and DD, and to identify and develop roles for new disciplines. This training to agency personnel should include ways in which all regional and community services can be used in serving the DD client.

3. The UAF should provide excellent examples of service provisions which should be available to the DD.

4. Ongoing research activities which relate to the provision of service to the DD.

5. Assistance to the states, regions, and communities so they reach their goals in respect to the needs of the DD (Hammer and Richmond, 1977a; and *UAFs* - DHEW, 1972).

The role of the UAF, then, appears to be one of supplying the service, training, and education to all DD clients, no matter what age or disability. From the preceding presentations which speak to problems in client identification, lack of service coordination, and attitudinal problems regarding both aged and DD groups, it seems appropriate to raise questions concerning the effectiveness of the UAF in its various roles.

The UAF - Research Questions

From the previous presentation of a conceptual framework, one can ask questions concerning the UAF and its role in providing service and education to the AADD. These questions can be considered research objectives. Many of the same questions that were asked in the other sections of the larger research report are entirely relevant here. Others have been added in this particular paper to delineate the specific role of the UAF in relationship to its educational capacity.

1. Are UAF's supplying services to AADD clients?

2. Do UAF's feel there is a problem in service delivery and education as regards the AADD client?

3. What direct services are being provided to AADD clients?

4. What are the unmet needs of this group?

5. Is the UAF able to prioritize the needs of the AADD client

6. What are the obstacles in meeting the needs of the AADD person

7. Does there appear to be a need for training in how to meet the established needs of the AADD person at the UAF level?

8. Is the identification of AADD clients an objective of the UAF?

9. Is information about the aging process supplied to the client as (s)he gets older?

10. Is the UAF involved in research activities concerning AADD?

11. Is the UAF seeking interdisciplinary training in areas that would impact on the AADD client?

12. Is the UAF providing interdisciplinary training in AADD at university, agency, and community levels?

METHODOLOGY

The author of this chapter has a background in gerontology and adult education. Therefore, the implications and discussions of the findings will be biased in specific areas.

It is also important to mention that since the author was not present from the initial implementation of this project, biases could possibly be present in terms of formulation of the research objectives and in interpretation of results. In other words, the discussion might possibly place different emphases on various issues than was the original intent of those initially involved in this research project.

The survey methodology was selected for the UAF part of the research problem. Forty-four UAFs were sent the original questionnaire which dealt with demographic information on the AADD, services available and impediments to service delivery. Additionally, however, each UAF was sent an addendum questionnaire along with the original one. This addendum questionnaire sought to assess the present role of the UAF in educating and training at all levels: UAF, university, agency, community, and individual client.

Although 32 UAFs sent back at least one or both of the survey forms, not all UAFs completed both forms. The response rate for returning at least one form was 77%. In terms of the first questionnaire--the original survey form sent to all respondents in the entire research project--32 respondents completed the form (response rate = 73%); the second addendum survey form was completed by 23 of the UAFs (response rate = 52%).

It should be noted that all percentages are only based on the participants completing the survey form that was relevant for that particular survey question. If the respondent was instructed not to complete a particular part of a survey, the incompleted section will not be considered in terms of the percentages of missing data. This would mean that on certain items on the first survey (assessment), the response rate would be based on 18 respondents. This was the case in the responses from some participants in the original survey.

The missing data problem might have been lessened if one form had been developed for the UAF. By giving two forms, respondents may have felt less of an obligation to do both of them. They also might have felt that one of the forms "didn't apply" to them. Also the two forms repeated some of the same information on each form.

It was requested that an administrator or research director be responsible for completing the forms and mailing them back to the researchers.

In the following analysis, only descriptive data was considered relevant, since the small size of the N and the high level of missing data precluded the use of inferential statistics. Findings will be presented in terms of percentages in both the text and the tables. Since the data is limited, no statistical significances can be discussed here. The data can only suggest possibilities related to the questions asked. Assumptions concerning the data cannot be related to cause and effect situations. One can only say the data appears to support or not support the research hypothesis proposed for further study.

There are significant ways in which the missing data problem could have been lessened. In terms of data collection, different procedures could have yielded greater and more complete responses. If greater attention had been paid to question format and the ordering of specific items, more precise information could possibly have been elicited. The main part of the research paper will deal with some of these issues more specificically.

FINDINGS/DISCUSSION

1. Are UAF's supplying services to AADD clients?

Both survey forms given to UAFs asked questions concerning services to AADD persons, and some of the UAF's did not fill out one or another of the survey forms. On the original survey form, 18/32 (56%) of the UAF's indicated that they were serving AADD persons, about the same as Revion V agencies surveyed by this project, of which 55.7% said they were serving AADD. Eight UAF's felt there were identified clients not presently receiving services. If these results are borne out in more detailed and sophisticated research projects, one will begin to understand why so many agencies list lack of trained staff in AADD as an obstacle to program implementation for this group. The U.A.F. is mandated to provide training and services in DD. If they do not see themselves as providers of service, then where will the agency go to seek such information? If only about half the UAFs are providing services to this group, is there any wonder agencies whom they are supposed to influence aren't doing any better?

2. Do UAF's feel there is a problem in service delivery and education as regards the AADD client?

On the Addendum questionnaire, 12/23 (52.2%) of the UAF's indicated that their UAF is not providing services to the AADD client. Of these, (43.5%) said their facility was not planning to extend services to this population.

In response to a question in the Addendum questionnaire as to whether a training workshop or module would be useful to the UAF training program, 15/23 (65.2%) of the UAF's said they had no such program, and 4 of these UAF's did not feel such a program would be useful. Another question as to whether training or staff development on the aging process was being provided by the gerontology department of the university prompted 7 UAF's to indicate that there was no programming at present and to assert that it would not be useful.

Therefore, there is some reason to believe that problems of attitude and awareness of the AADD population exist at the UAF level. In light of the diverse needs of such a group as the AADD, it seems quite clear that an increased level of awareness is crucially needed right at top bureaucratic levels of implementation of DD services. It must be mentioned here that a potential weakness in survey design could have contributed to these results.

In terms of people's ability to identify of AADD clients, some people might have felt their needs are being met in the UAF as part of the whole DD group. On these survey forms there was no way one could respond with a yes or no concerning service provision and identification and give reasons why one felt that way. For example, a question could have been asked: "Are you providing service?" and then another question, "Do you think it necessary to identify AADD clients so that needs are met?" An alternate question might have been, "Do you think the needs of AADD persons can be met even if they remain unidentified in terms of their age?" The question concerning whether a training module in AADD would be important could have been followed by a list of response categories for those who answered yes and another for those who answered no. This would have given much information as to why respondents felt the way they did.

3. What direct services are being provided to the AADD client?

Table 1 shows the types of services mentioned most often in relation to the AADD clients. It is evident that diagnostic assessments are the most frequently provided service (14/18) 77.8%, and educational classes for to the AADD client the least provided service (3/18) 5.6%. Only somewhat better were survey results from Region V which indicated that only 17.5% of the agencies provided educational classes to the AADD. It appears that diagnostic and information referrals are being made at a greater rate, but that treatment and educational services to back up the recommendations are lacking. Ongoing training and service are needed. Identification of an AADD person's needs is a beginning, but it is definitely an incomplete solution to his/her complex problems.

Table 1

Service Provided to the AADD Client by the UAF

TYPE OF SERVICE	% OF SERVICE PROVISION
Diagnostic Assessments	43.8
Information/Referral	40.6
Counseling	34.4
Medical Treatment	28.1
Vocational Classes	15.7
Education Classes	9.3

> The UAF program has had more limited success in uniformly accomplishing training in service settings fully responsive to the 1962 Panel's concept of "continuum of care." An entire life spectrum of services is needed by individuals with developmental disabilities. While there are exceptions, UAF's have tended to limit their emphasis to diagnosis, treatment planning and medical care. While the excellence of UAF's is valuable and indeed necessary in these areas, training needs must be extended to the full continuum of care. Also, UAF's need to consistently pay attention to adults who are developmentally disabled. (Tarjan, 1976, p. 4)

4. What are the unmet needs of this group?

Half of the UAF's, (9/18) 50%, said that there were unmet needs (from the original survey form). Five categories of needs were identified: sheltered employment, adult activities and recreation, medical treatment, dental treatment, and other residential care.

5. Is the UAF able to prioritize the needs of the AADD client?

There was no consistency among UAFs as to the services they provided to the AADD person. For example, two UAF's listed information and referral as the most frequently provided service and two others listed it as the least frequently supplied. Different funding sources and hence different emphases in particular UAF's might have resulted in some discrepancy here. However, professionals in UAFs may are not be sure of directions and priorities in meeting the needs of the AADD client.

Because only nine UAF's (9/18) 50% were able to hypothesize on the needs of clients if additional funds were available, it appears that there is no clear direction as to what AADD client needs are, even though lack of funding was cited as the major impediment to service (21/32) 65.6%.

When asked what services they would supply if there were funds, UAF's mentioned counseling and treatment most often. But when asked what client needs were not being met, no respondent mentioned counseling and treatment. Similarly, dental treatment and income maintenance were also mentioned as needs to be met if funds were available, but were not mentioned as unmet client needs. Of those UAF's who have plans underway to extend services to this population, no respondent mentioned sheltered employment, although respondents indicated this as an area of unmet need, and an area of emphasis if funds were available.

Finally, only (9/18) 50% of the UAF's felt they could identify AADD clients who should receive services but who were presently not getting them.

It is certainly worthy of further study to determine if priortization of needs is important in serving the AADD population. It becomes even more imperative when Gordon's (1977) study is considered. He determined that only 4 needed services were presently being provided to the AADD population, but that future needed services would average 23. He also found that although there were differences in types of health problems due to disability type " . . . generally the total array of problems and amount of services needed did not significantly differ according to disability category or geographic location" (p. 13). If this is true, both presently provided services and those which the UAF anticipates as needed by the AADD group in the future should be carefully assessed.

6. What are the obstacles in meeting the needs of the AADD?

Table 2 indicates that lack of funds was the most often cited impediment to delivery of services 21/32 (65.6%). Apparently, lack of definition of the AADD group, inability to identify these clients, and absense of consensus or the priority of their service needs did preclude UAF's from asking for additional funds. One would have thought that applying for funding, would have required that the target population be clearly identified and their service needs clearly set forth.

Table 2

Major Problems in Service Provision to AADD Clients

PROBLEM	% OF THOSE INDICATING THIS IS A PROBLEM
Inadequate Funds	65.6
Staff Training & Development	46.9
Transportation	43.8
Lack of Community Support Services	43.8
Difficulty of Finding Qualified Staff	25.0
Attitude of Community toward Client	25.0

7. Does there appear to be a need for training in how to meet the established needs of the AADD at the UAF level?

Need for staff development and training was expressed by only ten of the thirty-two UAF's (31%). In those UAF's where plans were underway to serve the AADD population, only two UAF's (8.7%) appeared to be including UAF staff training and development as a priority. Twelve UAF's (52.2%) felt a training workshop in AADD would be useful. Fifteen UAF's (46.9%)

felt staff training and development was a major problem in service delivery; eight UAF's (25%) felt there was difficulty in finding qualified staff. This evidence supports the contention that such training is unavailable. In the survey of Region V, agencies both lack of qualified staff and staff training and development were major problems in providing service in 23% of the agencies surveyed. These figures could be quite conservative because they reflected only those UAF's who admitted there were specific unmet needs of the AADD client. Those who did not see service provision to this group as a problem would not respond to questions having to do with meeting needs.

8. Is the identification of AADD clients an objective of the UAF?

Table 3 indicates that the percentage of agencies (72.2%) who could identify the number of younger adult clients served (72.2%) dropped off significantly for the 55-64 and the 65 and older categories, to less than 40% of agencies able to identify the number of clients being served.

Table 3

UAFs who Supplied Client ID Information

1. Identification of the Number of Serviced Clients by Age Category	% OF THOSE SUPPLYING INFORMATION
35-54	72.2
55-64	38.9
65 and older	33.3

2. Identification of Client by Disability Type	% OF THOSE SUPPLYING INFORMATION
Epilepsy	22.2
Cerebral Palsy	22.2
Autism	5.6
Mental Retardation	66.7
Multiply Handicapped	22.2

Although 66.7% of the UAFs could identify the disability type of clients who were mentally retarded, significantly fewer agencies could supply information about other disability types (see Table 3).

Respondents who did not feel service provision to the AADD client was relevant to their situations skipped these questions. The percentages only reflect those who felt service provision was part of their mandate. Eighteen of the UAFs were qualified to complete the question regarding client identification by disability type. Of these respondents, only 6/18 (33.3%) were able to give the reason why AADD clients coulld not be identified by disability type, for example because of no records beingg maintained.

It is significant here to refer back to the research hypothesis which dealt with most frequently provided service. It was found that 43.8% of UAF's supplied diagnostic services. Yet where does this information go to be utilized? Is the diagnosis made and the information dropped? Such data is essential if the agency or U.A.F. is to begin to consider the needs of the individual AADD client. Without it treatment would be "hit or miss." As mentioned earlier, it is not community placement per se which determines quality of life, but the meeting of individual needs.

9. Is aging information about the aging process supplied to the client as s(he) gets older?

Table 4 shows that some information about aging is being supplied to all age groups. Since most UAF's receive funding which emphasizes serving DD persons through young adulthood, it is interesting and somewhat optimistic to note that 69.6% of UAFs were supplying some aging information on aging to their adolescent clients. The relatively high percentage supplying information on aging to infants and children is interesting also. Since the family is most often responsible for the care and education of their DD child, it is hopeful that such early information concerning the importance of lifelong planning will result in better care and services at all life stages. As Gordon (1977) mentions, " . . . the neglected specialized needs of young DD persons have a direct bearing on the needs of older DD persons" (p. 2).

Table 4

Age Group to Which Aging Information is Supplied

AGE GROUP	At Least Some Info. Supplied	No Info. Supplied	Non-Respondents to This Question
Infant (0-5)	52.2%	21.7%	47.8%
Child (6-11)	65.2%	8.7%	34.8%
Adolescent (12-19)	69.6%	0.0%	30.4%
Young Adult (20-30)	60.9%	8.7%	39.1%
Older Adult (31-64)	56.5%	13.0%	43.5%
Aged Adult (65+)	52.2%	21.7%	47.8%

The missing data figures in Table 4 reflect those survey respondents who did not complete this question on the addendum survey. Significantly, less than half (43.5%) of the UAFs did not say whether information on aging was being supplied to older DD adult (ages 31-64).

Lower percentages could reflect the fact that UAFs presently do not serve these groups as frequently. The low overall percentages and missing data values might also mean that few people in the UAF are in a position to supply this information. The fact that 25% of UAFs had difficulty in locating qualified staff in the AADD area may be causing a shortage of personnel to develop educational programs for different age groups.

10. Is the UAF involved in research activities concerning AADD?

Five of 23 (21.7%) of the UAF's said they were engaged in research activities in the area of gerontology and DD. Eighteen of 23 (78.2%) said they were not engaged in these research activities. Research projects seemed to be limited to the five UAF's with special aging projects.

11. Is the UAF seeking interdisciplinary training in areas that would impact on the AADD client?

Over half (52.2%) of the UAF's felt a training module in AADD would be useful to their programs (see Table 5). Only 17.4% (4/23) of the UAF's indicated that they had cooperative arrangements with other university programs (i.e., gerontology departments) to provide training or services in the area of AADD. No UAF indicated that inservice training or staff development on the aging process was provided to UAF staff by the gerontology department in a university. Only 47.8% (11/23) UAF's felt this training would be useful to them, and 30.4% (7/23) felt this training would not be useful. Five of the UAF's which responded to this form did not respond to this question.

Table 5

Training Needs in AADD Supplied by UAF

Usefulness of an aging/DD module Training Program	52.2%
Present use of AADD module	13.0%
Implementation of Aging Research Projects	21.7%
Cooperative Arrangements in AADD with a University	17.4%
Unit on DD for University Gerontology Staff	0.0%
Cooperative Arrangements with Community Agencies	4.3%

12. Is the UAF providing interdisciplinary training in AADD at university, agency, and community levels?

No respondent indicated inservice training in DD was being supplied to the gerontology department on the university campus. Only 17.4% (4/23) of the respondents indicated that they had cooperative arrangements with other university programs to supply training or service to AADD (see Table 5). Only one agency indicated inservice training, services, or field practice experiences were supplied on a cooperative basis with community service agencies, and only 21.7% (5/23) of UAF's indicated that they were providing inservice training or staff development in DD to community agencies serving the aged.

> Interdisciplinary training is a basic essential in the effort to prepare leaders and certain other personnel who will work effectively with the complex problems associated with mental retardation and other types of developmental disabilities" (Tarjan, 1976, p.7).

There seems to be a dearth of UAF interdisciplinary training fo service to the AADD at different levels. If we compare it with another statement by Tarjan, one begins to wonder whether an "impressive array of affiliations" is really useful or effective in meeting the needs of the AADD. "Intermeshing of UAF program activities into local and state service settings beyond the physical bounds of UAF's is evidenced by an impressive array of affiliations with health, education, social and rehabilitative, and policy planning agencies" (Tarjan, 1976, p. 10).

In a Core Curriculum Survey developed by the Steering Committee for planning the Fourth National Conference of UAF Training Directors, it was found that Geriatric Developmental Disabilities was the subject area least often taught in the UAF. The purpose of including this content area in the survey was to assess the degree to which factors related to the DD person's adjustment to life as (s)he grew older were reflected in the core curriculum of the UAF (Cox, 1978).

Generally speaking, it appeared that about half the UAF's were supplying services to AADD. It should be remembered, however, that all UAF's are, by the nature of their funding requirements, somewhat limited to serving children or adolescents. But what must also be considered is the responsibility of the UAF in pressing for changes in the present funding practices. Beyond service to the AADD population the descriptive data suggest that further research should be done to determine if there are significant problems in identifying AADD client needs, prioritizing these needs, and in determining present attitudes about the AADD at all levels, including the UAF level.

Even though the compilation of demographic information would seem valuable in determining the magnitude of specific problems at particular ages, such does not appear to be the case. There does not appear to be much individualizing or even rough grouping of AADD clients. Even in light of this, UAF's indicated that their most supplied services include diagnostic assessments, information and referral, ongoing counseling and treatment. Effective delivery of these services would seem to require individualization to the needs of each client. Is it possible to meet individual client needs and still only be able to categorize approximately half of the older DD clients by disability type?

Though research has shown that many older DD clients have multiple handicaps that increase with age, only 12.5% (4/32) of the UAF's felt individualized program plans are crucial to providing services to the AADD. Thus, many of the UAFs seemed to underplay the importance of the individualized program plans and were apparently unaware of the fact that these plans are required by law.

> The DD Law of 1975 . . . includes three interrelated mechanisms to assist states in protecting an individual's rights to quality services appropriate for his/her needs: Individualized Habilitation Plan, Evaluation System, and Advocacy and Protective Services . . .
>
> The Individual Habilitation Plan . . . sets forth a prescription of programming action tailored to the individual needs. Technically, the DD law only requires an IHP of persons with DD, receiving services funded in part by DD funds. However, the IHP concept . . . is included in several major Federal programs including vocational rehabilitation and social services (Hammer & Richmond, 1977a, sec. 5.44).

Lack of response was to be a problem on some questions relevant to the research objectives. All the "no information supplied" values were based only on the results of those respondents who completed the appropriate survey in which the question was asked (see Table 4). This lack of response was particularly high for identification of AADD client disability type. This would seem to indicate some lack of information as to the specific problems the AADD client brings to the UAF.

As previously mentioned, however, lack of response could also be related to weaknessses in survery design. Both questionnaire format and style of questioning could have been improved. Although the original questionnaire was pretested, the addendum was not. If it had been, some of the problems concerning operationalizing the research objectives could have been eliminated.

It is necessary to reiterate the fact that this particular study is limited in that it dealt only with percentages that could possibly have bearing on cause. It cannot be generalized unless verified by further research.

If confusion as to the availability of demographic data and priorities of needs and service provision does exist, as further research must substantiate, then the implications of this in terms of training needs at all levels will be manifold. The data suggest that little training in the AADD area is being done, even though the DD Act specifically mandates service to those previously denied service and even though UAF procedures mandate training in all areas of concern in DD.

IMPLICATIONS

It appears that very few UAF's are supplying leadership in training for service to AADD persons. Many factors could be contributing to this: UAF attitudes about the population and attitudes at other levels; a dearth of knowledge concerning the problem and how to go about solving it; a lack of awareness of how to "train the trainers"--those in the UAF who are to lead; insufficient pressure from the AADD population or those advocating for it for solutions to problems; a lack of funds, or finding guidelines which limit the use of monies; and the inability of the UAF as an organization to change in the face of changing needs.

If the process of social change and its relationship to policy formulation is made clear, then many of the issues just reiterated can be better understood.

Obstacles to Social Change

Those social forces which impede social change are many and varied. Burrello (1979) argues that bureaucratic structures (e.g., UAF) strongly "restrain the forces of change" (p. 61). When a structure must deal in a highly specialized service area, any changes in this area pose a threat. A major part of the support for UAF programs is earmarked for training and for service to developmentally disabled children. As a result the AADD person, although very much a part of the DD legislative mandate to UAF's, is considered a threat to the established organization.

Minorities are often overlooked in allocating resources, and because of this advocacy and lobbying groups have to be developed. Usually, funding of programs, etc., has been dependent on a particular interest group's identity to which "ear-marked appropriations could be connected" (Burrello, 1979, p. 63). Because the AADD population needs are so different from those of the younger age group, and because established institutional systems (e.g., special education) do not often serve them, the AADD population is really a minority group within a minority group! The present DD advocacy group's objectives do not mesh with the needs of the AADD client, and therefore there is no real advocate.

Service providers within agencies or UAF's, may themselves favor or oppose social change. A strong relationship between attitude toward social change and effectiveness of agency objectives may exist. Generally there are two purposes of any organization: one is to accomplish the stated goals and objectives of the organization; the other is to meet the personal needs of the people in the organization. The place of education in effecting relevant organizational objectives is important in both of these areas. First of all, education and skill development are needed to help the staff accomplish their assigned goals. Secondly, by helping develop self-awareness, the staff can see their own personal needs in light of organizational goals and structures.

Handley (1975) speaks to the necessity of the UAF's getting involved in community service programs; his report is particularly relevant to the needs of the AADD client who is being placed in the community, who requires continuing and multiple service individualized to his or her needs, and who is faced with many negative social attitudes toward the aged and the disabled. Listed below are some of Handley's suggestions.

Training programs are imperative if the needs of DD persons in the community are to be met. Mandated changes in community services make demands on both the UAF and the community agency. Several factors affect the design of training and educational programs for university students in the UAF and for community agency staff who are delivering the service.

1. There are definite, mandated services to the DD, but there are not enough trained personnel. Therefore, efforts to resolve problems (e.g., meeting needs of AADD) are fragmented and crisis oriented.
2. Budget limitations produce demands on personnel and the necessary training is often lacking.
3. There are not as many students in particular disciplines because of a changing labor market.
4. Agency personnel are often limited in their training in particular areas, but they still provide service to DD.
5. Time lags exist between innovation in technology and service to DD.
6. Community-based residences and programs for DD persons find there are limitations when they get into the community. This is due to limited or no service provision, and inexperienced and untrained agency staff.

Certain "realities" in the UAF also seem to preclude service to all DD persons living in the community, including the AADD population.

1. UAF's have not considered training, inservice, and continuing education needs in terms of community people serving the DD.
2. Because there is a dearth of demographic information about the needs of the DD people in the community, the UAF often selects easily identified groups to service. This happens even though the needs of the AADD are often multiple.
3. Trainers in UAF's lack experience, knowledge, and commitment to be trainers in the community.
4. There is a lack of empathy and understanding concerning

the ethnic differences of clients.

5. Adult learners in the community differ from university students. Therefore, techniques and methods must be different. UAF's do not emphasize these differences in learning styles and learning needs.

6. Because the UAF is often viewed as an "ivory tower," bad impressions are often intensified in the community because of ineffective training methods.

7. Interdisciplinary approaches in the community are often non-existent (Handley, 1975).

All of the above impede the process of social change and also slow the enactment of enabling legislation to meet the needs of this group.

Dybwad (1969) also discusses obstacles to change. He states that progress is often an obstacle to change. If the idea of community placement is taken as an example, then this can be better understood. Under the guise of this new movement we talk about community placement as the answer to the problems of all DD people without regard to their individual needs. We supply little ongoing in-service training of paraprofessional staff, but we feel self-righteous about advocating for the DD by supporting community placement. "The apparent conflict between the doctrine of least restrictive alternative and the delivery of specialized technical services will require a high level of interpretation and negotiation based on evidence, not rhetoric" (Burrello, 1979, p. 68).

Social forces which enhance change lead to a more optimistic outlook for the AADD population and for UAF service and training to help them.

Human Services Revolution

Rhodes (in Burrello, 1979) predicts that a revolution will take place in human services and in the caretaker-client relationship. Right now there is a unilateral and unequal dimension to this relationship. Despite funding and training, this basic relationship is not working. "While the specific focus of Rhodes' predictions is on deviations in children, the social climate that he describes as possibly leading to major changes in service systems is much broader, encompassing the totality of relationships to individuals and society" (Burrello, 1979, p. 34).

This pervasive change has profound implications for the UAF. It implies that the organization must be sensitive to the needs of the AADD client directly and indirectly. It implies a social change orientation (Dybwad, 1969). If people are committed to the meeting of organizational objectives, then they must make a conscientious commitment to promote change as it is needed and to understand the change process in relation to their disciplines.

External Pressure

Rothman argues that organizations are insulated by the amount of time it takes to obtain feedback from the environment (e.g., client) in terms of program effectiveness, the meeting of needs, etc. This is especially significant in the human-service organization where sensitivity and awareness are particularly important to effectiveness. "Feedback may be heightened by activating elements of the environment to send immediate responses on operations to relevant staff members, administrators, or citizen officers" (Rothman, 1974, p. 124). Such an approach also utilizes the change orientation.

Advocacy for the AADD population is very important. A constituency should be developed that is committed to the AADD, able to compete for the limited funds available (Burr, 1975),and willing to facilitate changes in social attitudes toward the handicapped in general, and the AADD in particular.

It is not only for public awareness that advocacy groups should work, but also for effective service.

> . . . members of voluntary associations (concerned with advocacy) must be militant; they must monitor publicly financed programs presently available, develop program safeguards, gain membership on governing and advisory boards, establish independent groupings to act as a watchdog on services, and fix legal mandates for services (Kurtz, 1977, p. 145).

The aged themselves have emerged as an effective political force. The aged and the disabled should coordinate their efforts so that they can effectively and efficiently support each others positions (McCallister, 1975).

Funding Procedures

Like Rhodes, Barr (1978) feels there is a unique national, economic, and political climate, supporting the ideas of advocates for the handicapped and promoting candidates sympathetic to DD issues. The advocacy role is important here in lobbying at all levels of government support of programs in UAF's. Barr says there is a need for planning "with a proactive emphasis rather than a reactive emphasis" (p. 89). If the UAF's are sensitive to the needs of the AADD population, then such a proactive emphasis can really happen. But if UAF's lack awareness of this population, as this present survey seems to substantiate, then the role of the UAF can only be reactive and crisis oriented. This crisis orientation could ultimately result in a reduction of funds to UAF's if they do not meet existing legislative mandates to all DD persons.

Dybwad (1969) speaks to the government's need to be more discriminating in its granting and funding procedures. These monies should be supplied more selectively. The following quote has particular relevance to the UAF role in change and its specific role in servicing the AADD client. "Thus, grants could be awarded to institutions that have shown evidence of their willingness to change, rather than to make awards in the hope that these will lead to change" (Dybwad, 1969, p. 399).

The UAF is a particularly relevant organization to the AADD client. It would do well to be sensitive to change, and in being sensitive to change, to become sensitive to the AADD issue which is at the moment challenging the status quo.

If the UAF can respond to this challenge constructively, then it will be contributing to positive social change. If it considers such a challenge a threat, then the possibility of funding loss could be a very possible result. Rothman (1974) points out that human-service organizations need to receive legitimization from the public. The public, in the person of a government funding agency, can challenge an organization (e.g., UAF), and alter the organization's goals by manipulating its resource supply (funds). A change in goal emphasis--here service and training for service to the AADD population--might result in continuing funding; refusal to change might result in loss of funding entirely.

Barr (1978) discusses how funding procedures can be facilitated through cooperation among UAF's and through lobbying at all governmental levels. Barr considers it important that UAF's

> work together to tie standard setting to predictable consequences by the bodies who are concerned with standard setting and funding. If the standards are met, then funding should follow without constraint. If the standards are not met, then they [University Affiliated Programs] should be helped to meet the standards or suffer the consequences of loss of support (Barr, 1978, p. 94).

The role of the UAF as a positive change agent was already established at the time of the 1962 President's Panel [illegible] The UAF must create for itself a new image as a change agent and incorporate this goal as a primary program mission (Tarjan, 1976, p. 4).

UAF Standards

Some current changes within the UAF organizations have potential for positive social policy changes in regard to the AADD. The Federal Government (DDO) allocated the Fiscal Year 1979 funds for the development of standards for programs funded under Developmental Disabilities Act Authority. Under current legislation, PL.95-602 the Dept. of HEW is required to produce the standards within six months of the passage of that law. At the 1978 Annual Fall meeting of the AAUAP-MRRC in Seattle, members voted on UAP standards that were under development by the Association's Program Standards Committee. Such maintenance of general standards can do nothing but enhance service to the AADD population. (UAP Reporter, September - October 1978).

UAF Database

Fiscal year 1978 was the transition year for the UAF Database. "The project will continue to refine the operation of the centralized databank on the resources and activities of UAP's. The Database is also supporting the Association's efforts in the development of performance standards by providing quantitative information on UAP's" (UAP Reporter, Mar - April 1978, p. 10).

The Database Plan (Jacobs and Guthrie, 1977 and Helmich and Lupo-Greene, 1978) could become more responsive to needs of the AADD population by supplying more precise categories of information as to the demographics of the older DD population and service provision to this group. There is presently no way of retrieving from the Database the UAP Special Training

Programs that could possibly be going on in the area of gerontology and DD or educational gerontology and DD. Such programs, if they do exist, would be listed under the other category. If a special category were established, information of this type could be supplied in the future. Currently, if the UAF's were to publish any material in relation to the AADD population it would not be retrievable because there is no specific category for material on this topic except the Other category.

In terms of UAP faculty information, there is no category such as Gerontologist which would be sufficiently specific to make resources available at the UAP concerning AADD concerns. Again, such information is listed in the Other category. Academic affiliations specific to gerontology are also not available. Finally, in terms of services to clients, there is no way of knowing how many clients at specific age groups distribute themselves across the different types of DD. Such information would be valuable because of the overlapping handicaps that can become especially profound as the DD client gets older. The reorganization of the Database's program and priorities is an optimistic sign for improved service to all DD persons, but is an especially valuable resource for researchers studying the AADD population and its needs.

Summary

From the results of this survey and from an extensive analysis of the literature, it is quite clear tht the UAF has a challenge to meet in its service and educational role in meeting the needs of the AADD clientele. It is important that future research deal with the specific UAF system and how it can become vitally involved in the AADD area. It is also important that additional research be done to assess the current role of the UAF in meeting the needs of the AADD client. This present study has provided some direction, but further research must be more precise and informative as to specific demographics and AADD client needs being met. Additionally, research should be done to assess the impact the UAF has on the community and its relationship with the DD person. Continuum of care and quality of life are important issues to all DD and they are critical to the AADD. If the UAF can become more sensitive to community needs in serving the AADD, these core issues can become a reality.

To be effective in meeting community needs of the DD it is necessary to review needs of the clients, assess additional needs, develop action plans, and talk with other UAF's (Handley, 1975). The implications of these directives cannot be underestimated. They inherently affect the service provisions to AADD clients, and are far-reaching in their potential impact.

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CRITERIA FOR DESIGNING TRAINING PROGRAMS FOR PRIMARY CARE WORKERS

Judy Cooper

Rationale

Throughout the preceding papers, a lack of training opportunities is noted. Sweeney states that "Attitudes are still a major obstacle to service." Why is this so? If attitudes need to be addressed, then better training is the most promising strategy. Certainly Thurman's chapter points to the need for UAF's to provide better training for the practitioners serving AADD persons. How is this training to be provided? How is the training model to be designed?

Client Needs

In order to develop an adequate training model, one must first examine the needs of the population being served. The aging and aged, developmentally disabled are certainly not a homogeneous group. In a survey conducted by the Research Project on Aging at the Athens Unit Georgia Retardation Center, Hartig and Carswell (1979) found persons who had been labelled as aging and developmentally disabled who ranged in physical status from "good or excellent" to "confined to bed and requiring full time medical assistance." Economic resources varied from "ample with reserve" to "destitute." It was noted that the wide range of client functioning levels and of community and family attitudes made the multiplicities of individual needs even less homogeneous.

An aging or aged, developmentally disabled person is a multiply handicapped individual. An overlapping occurs between disabilities created by the handicapping conditions and disabilities that occur as a result of the natural aging process. Stereotyping and role expectations about disabled persons are compounded when stereotypes about the abilities (or lack of abilities) of aging persons are introduced. When primary caregivers cannot separate stereotypes from facts, they lower their expectations of clients. Factual information is needed to help workers identify care areas, to help them understand special problems that may be occurring, and to aid in creating a purpose for remedial treatment rather than mere maintenance.

Attitudes of Care Workers

A second issue that needs to be considered is that of the primary care worker's attitude toward his or her job. It is common knowledge that staff turnover is high in facilities serving either the developmentally disabled or the aging. When staff turnover is high there are fewer care workers who can move beyond basic, minimal care toward increasing their knowledge and improving their skills. Worker attitudes play a major role in the quality of care a client receives. Misconceptions about disabilities, discomfort with handicapping conditions, and lack of understanding of their own responsibilities may cause direct care workers to become dispirited and possibly neglectful of their clients.

Kallstrom (1979) discussed the educational needs of a well-qualified human service technician, and reviewed three areas for training: knowledge, skills, attitudes, and values. He emphasizes that without addressing the attitudes and values of the worker, knowledge and skills cannot be put to the most effective use. Attitudes and values include - believing that people can learn regardless of disability or age, believing in the least restrictive alternative, and respecting the values of the client and family. In addition, the worker needs to feel good about him/herself. Feeling that one's job is worthwhile is necessary to improve skills and to persevere when a job becomes routine.

Training the primary care worker must include an examination of those factors that relate to attitude on the job. The worker should be given the opportunity to examine his or her own attitudes and should also understand what their particular job description is and why it was developed. In addition, the primary care worker should understand the philosophy and the organizational structure of the agency. Lines of communication need to be clearly defined and the worker should know where he/she can go with a problem.

Organizational Support for Direct Care Workers

A third related factor that needs to be considered in planning for appropriate training experiences for the direct care worker is the understanding and input from other persons in the organization. Training is needed at all levels in the organizational hierarchy. Supervisors need to understand their role in relation to the direct care worker, and should be resources as well as communication links. Support persons need to know what the specific problems are in the care setting so that they can in turn provide adequate intervention. Administrators need exposure to training programs so they can improve communication and provide sanction and funding. Supervisors should be included in training experiences for direct care workers so the supervisors can understand how their own roles and their employees' expectations are being changed.

In planning a training program for the primary caregiver, basic assumptions need to be incorporated into the design. It should be assumed that aging, developmentally disabled persons have the right to a safe, fulfilled old age, and that personnel who provide services to this group should relate to the clients in an appropriate manner. Staff acceptance of developmental disabilities and the aging process is a protection against mistreatment of the client by psychological, emotional, or physical neglect and abuse. A final assumption is that staff themselves must have a meaningful purpose, be officially recognized, and feel worthwhile if they are to provide improved services.

In addition to their basic orientation, direct care workers should have the opportunity for ongoing inservice training. Ongoing training should start with a basic model which can be modified for individual needs.

Individualizing the Training Model

A training program for direct caregivers in home care settings for the aged and aging developmentally disabled needs to be individualized. Combining information on *both* aging and developmental disabilities is important and produces a unique training program. Participants in a training program should be exposed to information in four basic areas: 1. agency organization and communication; 2. facts about the aging, developmentally disabled; 3. techniques for improved direct care; and 4. methods of coping with on-the-job Stress.

The training component about agency organization and communication should provide a basic orientation and should include an explanation of the direct care workers' job descriptions. Supervisory staff could be included to explain their role, the agency's hierarchy, and lines of communication. Trainees should be given an opportunity to share what they like and don't like about their jobs. In subsequent sessions, workers could examine specific issues and engage in problem-solving activities, thus increasing opportunities to improve on-the-job communication.

In teaching facts about the aging and aged developmentally disabled, trainers should combine basic facts with experiences designed to sensitize them to the needs of this population. Direct care workers need not be exposed to information that is not relevant to their jobs. For example, if seizures are not a problem in a particular group home but many of the residents have potential orthopedic problems, then training should focus on motor development. Individualizing training makes it more meaningful for the direct care worker. Sensitizing experiences should address stereotyping, role expectations, labelling, and the worker's comfort with and attitude towards the aging and aged, developmentally disabled person.

Training the worker to improve direct care services to clients should provide information about specific care techniques, as well as about client/worker communciation, attitudes, and role expectations. While specific techniques are certainly useful in caring for the aged, developmentally disabled person, communication can make the difference between routine care and habilitation-oriented intervention. Trainers should be able to demonstrate ways to provide humanistic treatment without disruption to the schedule or routine of any situation.

Direct care workers should be trained in verbal and nonverbal communication techniques in expressive and receptive areas. The direct care worker should learn ways to communicate his/her purpose to the client, enhancing mutual respect.

Ongoing inservice training could examine specific issues, and workers could engage in relevant problem solving activities.

The final component should examine factors that relate to stress and dissatisfaction on the job. Direct care workers need to feel good about their jobs and should know why they are needed. They should also learn to recognize the factors that may increase stress or feelings of worthlessness. Caring for the aging, developmentally disabled person is not always easy. There may be difficult and even revulsive experiences. Direct care workers must learn to recognize that having bad feelings about certain clients or situations is normal, but they should also be taught techniques for changing or coping with those feelings. Ongoing inservice training could include problem solving, opportunities to learn about other facilities, and coping strategies.

A training model should include time lines, goals, specific objectives, and materials needed for training. Participants should have the opportunity to engage in a variety of activities that provide information specific to their situations as well as general information.

Conclusion

Inservice training for direct care workers is only one of the many ways that services to aging and aged, developmentally disabled persons could be improved, but it is a very important way. Studies may indicate a need for improved services and administrators may conceptualize ideal situations, but if programs aren't implemented effectively at the client level, all the planning in the world won't help. Direct care workers have more responsibility for the treatment of the aging or aged, developmentally disabled person, yet they are often the most neglected group in the organizational hierarchy. Because they are continually on the job caring for the client, they have fewer opportunities than their supervisors and administrators to develop new skills. A well-planned training program with ongoing opportunities for professional development can help the worker become aware of new techniques and be a part of the planning as well as implementation process.

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Appendix A

SURVEY QUESTIONNAIRES

**INSTITUTE FOR THE STUDY OF MENTAL RETARDATION
AND RELATED DISABILITIES**

ISMRRD

The University of Michigan
130 South First Street
Ann Arbor, Michigan 48109

Dear Sir or Madam:

Over a month ago, you were mailed our questionnaire titled "Assessment of Community Services for Older/Aged Developmentally Disabled Persons". The data we have been receiving will help provide a base for future planning and decision-making for the older and aged developmentally disabled population. In order to make our planning and decision-making more accurate, it is necessary to collect as much information as possible. You may have felt the questionnaire was not applicable to you; however, even if you do not provide direct services or have a record of the data needed for the questionnaire, it is important for us to know that in order to justify further program planning.

The questionnaire sent previously may have been misplaced by now. For this reason, another copy has been enclosed in this envelope. Thank you for your cooperation.

Sincerely,

Nola Thomas

Nola Thomas, M.S.W., A.C.S.W.
Principal Investigator
Aging/DD Project

NT/mr

Enclosure

Telephone 313/763-3171

INSTITUTE FOR THE STUDY OF MENTAL RETARDATION AND RELATED DISABILITIES

ISMRRD

The University of Michigan
130 South First Street
Ann Arbor, Michigan 48109

ASSESSMENT OF COMMUNITY SERVICES FOR OLDER/AGED DEVELOPMENTALLY DISABLED PERSONS: A QUESTIONNAIRE

The Institute for the Study of Mental Retardation and Related Disabilities (ISMRRD), an affiliate of the University of Michigan, is one of a nationwide network of designated University Affiliated Facilities which receives support from the federal government to expand interdisciplinary training, services, and research activities in the field of developmental disabilities.

ISMRRD recently received a three-year grant from the Office of Developmental Disabilities (HEW)[1] aimed at increasing knowledge and expertise about the older/aged developmentally disabled population and services designed to meet its needs, as well as at stimulating development of innovative programs. In order to accomplish the project's long range goal of improving the quality of life for these clients, one of its objectives is to collect, organize, and disseminate data which will provide a base for future planning and decision-making in this area. As a part of this effort, we are conducting a survey designed:

(1) to determine the number of older/aged developmentally disabled persons served by each public or private agency selected;

(2) to identify existing services available for this group;

(3) to determine additional services they require, and;

(4) to identify obstacles/barriers to effective service delivery.

Your participation in this study is sought because 1) you now provide and will likely continue to provide services to developmentally disabled persons, or 2) you provide services which, under Section 504 of the Rehabilitation Act of 1973, we expect you will be making accessible to all disabled persons.

The findings of this survey will be used to develop guidelines for legislators and planners responsible for obtaining and allocating funds for services to these clients, and to provide a rational basis for improving services to older/aged developmentally disabled persons. In addition, we will be pooling information with other University affiliated projects conducting similar surveys in Georgia, Oregon, Utah, and Nebraska, in an effort to identify common problem areas and to generate possible solutions.

Please complete the attached questionnaire and return it to ISMRRD in the enclosed, stamped envelope. If your agency consists of units, (i.e., has a number of caseworkers who provide direct service to clients) which could more easily supply the information requested, please call for additional questionnaires. In addition, if

---

[1] "Serving Aging and Aged Developmentally Disabled Persons"
Grant #54-P-71134/501

Telephone 313/763-3171

your facility is a school, college, or university, please report only ongoing programs serving developmentally disabled persons. Do not include service delivered by students having field experiences with agencies.

The information from each questionnaire will then be collated to represent your agency. The telephone number is (313) 763-4450.

All the findings and interpretations of the data will be shared with your agency. Thank you for your cooperation.

Nola Thomas, M.S.W., A.C.S.W.
Principal Investigator
Aging/DD Project

DEFINITIONS

The following definitions are abstracted from these sources:

1) Hammer, P., and Richman, G. "The Orientation Notebook" prepared by the Developmental Disabilities/Technical Assistance System at the University of North Carolina at Chapel Hill, and;
2) Public Law 91-517 as amended by Public Law 94-103.

Developmental Disabilities - As defined in the law, a disability of a person which is attributable to mental retardation, cerebral palsy, epilepsy, or autism, or any other condition found to be closely related to mental retardation, which results in similar impairment and requires similar treatment or services; originates before the age of eighteen; has continued or can be expected to continue indefinitely; and constitutes a substantial handicap to such person's ability to function normally in society.

Mental retardation is defined by the American Association on Mental Deficiency as "significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period."

Cerebral palsy is not a discrete disease entity but is a label applied to a group of symptoms resulting from brain damage. These symptoms are caused by damage to the portion of the brain controlling voluntary muscle movement. Thus the symptoms usually include awkward or jerky movements, irregular gait, and poor balance. Symptoms vary widely in severity from one individual to the next. In some individuals, the symptoms may be so mild as to be almost undetectable; other individuals may be severely handicapped, confined to a wheelchair, and requiring assistance with the most basic activities. Other manifestations of brain damage such as sensory disorders, seizures, mental retardation, learning difficulties, and behavior disorders may or may not be present.

Epilepsy is also not a clearly defined disease but rather a collection of symptoms. It encompasses a number of nervous system disorders centered in the brain and manifested by recurrent seizures. Seizures fall into three categories: grand mal, petit mal, and psychomotor. Onset can occur at any age and treatment usually consists of anti-convulsant therapy. The seizures are demonstrated in sudden but brief changes in the individual's consciousness. Involuntary falling often occurs.

Autism is characterized by withdrawal, inadequate interpersonal relationships, exceptional relationships to objects, language disorders, monotonously repetitive behavior, and, in many cases, apparent impairment in intellectual functioning. The etiology of the condition is not definitively understood and explanations vary from considering it an emotional disorder of psychotic proportions to a physical disorder of the central nervous system. Currently, a widely accepted view is that autism has an organic cause which is almost always apparent in the first three years of life.

These four conditions are grouped together under the heading of developmental disabilities in recognition of the commonality of service needs among individuals with chronic (and often multiple) handicapping conditions occurring at an early age.

Developmentally disabled persons often have overlapping handicaps. For instance, mentally retarded individuals frequently have epilepsy and/or cerebral palsy. However, the four developmental disabilities are defined above as separate entities. These definitions are not intended to be all-inclusive. They are provided to clarify terminology.

Assessment of Community Services
for the Older/Aged Developmentally Disabled Population

DIRECTIONS: The following questions require either a single choice response or selecting items that apply to a given question. However, you may write personal responses in the "other" (please specify) choice items. Please return the completed questionnaire to ISMRRD in the enclosed stamped, addressed envelope. Again, thank you for your cooperation.

1. Does your agency provide services for older/aged developmentally disabled persons, age 35 or over? (check one):

Yes________ No_________

If YES, please go to question 2;
If NO, please go to question 9.

2. Please indicate the age of your youngest developmentally disabled client: _____; oldest: _____

3. Please list the number of older/aged developmentally disabled clients served by your agency from January 1, 1977 through January 1, 1978 , by chronological age:

Age Category	35 - 54	55 - 64	65 & older	TOTAL
Number of Clients				

4. Please indicate the number of older/aged developmentally disabled clients served by your agency from January 1977 through January 1, 1978 , with each of the following handicapping conditions as primary diagnosis: (indicate number).

Number

_____ Epilepsy
_____ Cerebral Palsy
_____ Autism
_____ Mental Retardation
_____ Multiply handicapped

5. If you were unable to complete questions 3 and 4 above, please indicate why:

_____ Records not maintained by those categories
_____ Records not maintained in this office
_____ Categories not applicable to this agency
_____ Other (specify) ______________________________

6.a. Check which of the following services your agency provides to older/aged developmentally disabled clients: (check all that apply)

Educational classes (adult) ____
Vocational classes ____
Sheltered employment ____
Adult activities/recreation ____
Information/referral ____
Ongoing counseling/treatment ____
Medical treatment ____
Diagnostic assessments ____
Staff development/inservice training ____

Dental treatment ____
Transportation ____
Guardianship ____
Personal advocacy ____
In-home services ____
Legal services ____
Foster care ____
Other residential care ____
Income maintenance ____

Other (specify) ____________________

b. Of the above listed services that your agency offers to the older/aged developmentally disabled client, which service(s) are rendered most frequently? (List in order of frequency: 1=most frequent, 5=least frequent.)

1. ____________________
2. ____________________
3. ____________________
4. ____________________
5. ____________________

c. If additional staff and funds were available, what other services would your agency provide to meet the needs of the older/aged developmentally disabled client? (specify)

____

d. Has your agency identified client needs which are not being met?

Yes ______ No ______

If so, what are they? ____________________

7. Has your agency identified older/aged developmentally disabled clients who are currently not receiving services and should be getting them? (check one)

Yes ______ No ______

If YES, how many? (specify number or estimate) __________

8. What is your source of program funding? (check all that apply)

Federal ______ State ______

County ______ Private ______

Special grant (specify) ______________________________

9. What do you consider as major problems in providing services to older/aged developmentally disabled clients? (check all that apply)

Inadequate funds. . . . . ______
Transportation . . . . ______
Lack of community supportive services. . . . . ______
Attitude of community toward clients. . . . . ______
Client attitude. . . . . ______
Difficulty of finding qualified staff. . . . . ______
Staff training and development. . . . . ______
Difficulty of maintaining the staff. . . . . ______
Developing individualized program plans. . . . . ______
Certification and/or licensing. . . . . ______
Severity of clients' handicap precludes use of service. . . . ______
Other (specify) ______________________________

10. Name of agency ______________________________

Address ______________ City ______________ Zip ______

Location (county and state) ______________________________

Position of respondent ______________________________

Name of respondent (optional) ______________________________

Please return this questionnaire by to:

Nola Thomas, Principal Investigator
Aging/DD Project
ISMRRD
130 S. First
Ann Arbor, MI 48109

Please add additional comments/questions regarding the questionnaire on the back of this page.

INSTITUTE FOR THE STUDY OF MENTAL RETARDATION AND RELATED DISABILITIES

ISMRRD

The University of Michigan
130 South First Street
Ann Arbor, Michigan 48109

June 16, 1978

Dear Administrator:

Enclosed you will find a questionnaire entitled "Assessment of Community Services for Older/Aged Developmentally Disabled persons." Another questionnaire specifically designed for university affiliated programs relating to personnel training is also enclosed as an addendum. It is requested that you fill out both questionnaires. Detailed information regarding the purpose of the survey is provided on the questionnaire cover.

As the first questionnaire is also being sent to other university departments (e.g. continuing education), you may have already received a copy. Please fill out only one copy of each form.

Sincerely,

Nola Thomas

Nola Thomas, M.S.W.
Principal Investigator
Aging/DD Project

NT/mr

Enclosures

Telephone 313/763-3171

ADDENDUM QUESTIONNAIRE FOR UNIVERSITY AFFILIATED PROGRAMS

As a representative of a university affiliated program, please complete the following questions which relate to training and personnel preparation. See attached definitions of terminology for clarification.

1. Is your UAP providing services for older/aged developmentally disabled (DD) clients? YES_____ NO_____. If so, please describe.

2. If your facility is not presently providing services to older/aged DD clients, are plans underway to extend services to this population? YES_____ NO_____. If so, please identify services or programs you plan to initiate.

3. Within your program, do you conduct an interdisciplinary seminar on DD? YES_____ NO_____. If yes, is information on older and aged DD persons included as a module? YES_____ NO_____.

   Would a training workshop or module on aging/DD be useful to your program? YES_____ NO_____. If so, in what way?

4. Is your facility engaged in any research activities in the area of gerontology and DD? YES_____ NO_____. If so, please describe.

5. Does your facility have cooperative arrangements with other university programs (i.e., gerontology departments) to provide training and/or services in the areas of aging/DD? YES_____ NO_____. If so, please list these departments or units.

6. If your facility provides inservice training or staff development in DD to the gerontology department on your campus, please describe.

7. Is inservice training or staff development on the aging process provided to your staff by the gerontology unit or department in your university? YES_____ NO_____. If not, would such training be useful in your facility? YES_____ NO_____.

8. Does your facility have cooperative arrangements with community service agencies (i.e., community mental health programs) to provide training and/or services or field practice experiences in the area of aging/DD? YES_____ NO_____. If so, please list these agencies by function.

9. If your facility provides inservice training or staff development in DD to community agencies serving the aged, please describe.

10. Is the aging process considered to be an important variable in developing treatment or management plans for DD clients in the following age categories?

	Very Much	Some-what	Not at all
INFANT (0-5 years)			
CHILD (6-11)			
ADOLESCENT (12-19)			
YOUNG ADULT (20-30)			
OLDER ADULT (31-64)			
AGED ADULT (65+)			

QUESTIONS OR COMMENTS

Appendix B

POPULATION PROJECTIONS FOR AREAS SURVEYED

I. Source: Statistical Abstracts of the United States, 1976.

Projected U.S. Population by 1980

	Total	35-54	55-64	65+
	225,705,000	24,342,000	21,047,000	24,523,000
% by Age	100%	22%	9.2%	10.3%

Projected Region V Population for 1980

Ohio	11,675,000
Indiana	5,782,000
Illinois	12,256,000
Michigan	10,031,000
Wisconsin	4,930,000
Minnesota	4,245,000
Total for Region V	46,919,000

Population of Areas Surveyed (July 1, 1974)

Ohio:	Cincinnati	1,376,000
	Columbus	1,067,000
Michigan:	Detroit	4,434,000
	Marquette	< 100,000
Illinois:	Chicago	6,971,000
	Champaign	< 100,000
Wisconsin:	Milwaukee	1,415,000
	Madison	303,000
Minnesota:	Minneapolis/ St. Paul	2,011,000
	Duluth	262,000
Indiana:	Indianapolis	1,144,000
	Ft. Wayne	162,000

Total population of areas surveyed approximately 19,133,000 or 40.7% of total Region V population.

Economic Manpower Corporation Suggested Prevalence Rates for DD.

Severe DD = 2.08%

All DD = 4.30%

Estimate of Total AADD Persons Served

Number of AADD persons served by non-nursing homes = 7715

Average number of AADD persons served by reporting agencies = 128

Potential AADD persons served by other agencies in survey area (.56 x 442 x 128) = 30,444

Potential AADD persons served by nursing homes = 13,330

Potential AADD persons served if all agencies are assumed to be providing service equally = 43,774

Potential AADD persons 35+ in survey area = 341,428

$$\frac{43,774}{341,428}$$ = 12.8% of potentially AADD persons served*

*: Probably less as non-duplicated account cannot be assumed

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